

Our Children's Voice

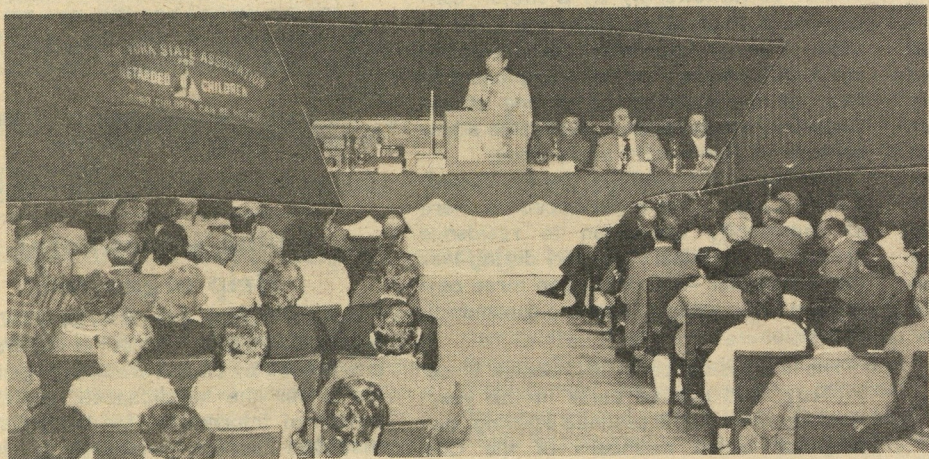
Retarded Children Can Be Helped

VOL. XXXV NO. 4

NEW YORK ASSOCIATION FOR RETARDED CHILDREN, INC.

DECEMBER 1983

The Challenge ahead defined at Lake Placid



Home concept most important says NYSARC

Sorting out how community residences can best parallel home life resulted in a Bill of Rights for mentally retarded persons living in community residences which was approved at the Convention.

The Preamble states: Mentally retarded persons have the same basic and legal rights as all other persons of the same age. It is the intent of this Bill of Rights to ensure that residents are provided an environment and atmosphere that assures these individuals a life of dignity.

Such rights are in no way diminished by the fact that such mentally retarded persons live in a Community Residence.

In order that such rights are assured and in no way curtailed, this Bill of Rights is promulgated. Such rights shall include but not be limited to the following:

1. The right to consider the residence as his or her home.
2. The right to receive and send communications freely.
3. The right to seek an alternative residential setting, either a new residence or a change in roommates, and to be involved in decisions regarding such changes.
4. The right to privacy and sufficient space for personal belongings.
5. The right to receive visits by families, friends, and guardians, and to make such visits, such rights include the right to privacy during such visits.
6. The right to be free from physical or psychological restraint or pressure.
7. The right to the dignity of risk such as the right to engage in appropriate activities although some risk is involved.
8. The right to a balanced and nutritious diet.
9. The right to appropriate medical and dental care and the right, either personally, or the parents or guardians, to a choice of the physician or dentist.
10. The right to appropriate clothing for age and season and the right to be involved in the selection.

11. The right to meaningful and productive work in his or her capacity.

12. The right to engage in meaningful activities if unable to participate in productive work.

13. The right to be regularly informed of their financial status and provided assistance in the use of their resources, as appropriate.

14. The right to the use of their personal money and property.

15. The right to access to meaningful recreation and community programs, and the right to participate in the planning of such activities.

16. The right to participate in the religion of their choice on an individual as well as a group basis, and to be encouraged to do so.

17. The right to receive assistance and guidance from staff.

18. The right to be exposed to specific or past programs in preparation for the exercise of the right to vote.

19. The right to participate with staff in the establishment of house rules.

20. The right of residents, their parents or guardians, to express grievances, concerns or suggestions, without fear of reprisals.

The residents, parents or guardians, shall have the right of Due Process and Review whenever the Provider proposes:

(A) To discharge or to move the resident,

(B) To move the resident.

These rights shall control the state in the promulgation of regulations and policies for community residences for mentally retarded persons.

FOR THE COMMITTEE ON RIGHTS:

I. Joseph Harris, Commissioner
Commission on Quality of Care
for the Mentally Disabled

Peter Knauss, Director
Bureau of Community Capital
Office of Mental Retardation
and Developmental Disabilities

Joseph T. Wingold
New York State Association
for Retarded Children, Inc.

Prisoners not good neighbors

A policy on Co-Location objecting to the practice of locating prisons on Developmental Center grounds was presented by Bernice Volaski, Developmental Chapter Committee Chairperson, and unanimously approved by the Board of Governors at the NYSARC Annual Convention in Lake Placid, New York. The policy states:

WHEREAS, NYSARC is strongly opposed to the current NYS policy of co-locating mentally retarded individuals with population groups which we believe pose a threat to their safety, such as prisoners or other populations under legal retention, in the same facilities for or in buildings in close proximity to one another,

WHEREAS, we believe that the rights of the mentally retarded are being violated by such actions of the NYS government; the mentally retarded are particularly vulnerable as a group and require, and should have, as society has, protection from potentially dangerous populations,

WHEREAS, it is important that the many strides made over the past several years in improvement of the quality of life for mentally retarded clients residing in Developmental Centers may be jeopardized by this policy of NYS. The needs of the mentally retarded are very special and particular. The ensuring of a way of life as close to the norm as possible, with all rights and benefits we all enjoy, is central to those needs,

WHEREAS, Court precedent and law have re-affirmed these civil rights of the mentally retarded and provided that they are entitled to live in "the least restrictive environment" as compatible with their clinical needs,

WHEREAS, this policy of co-locating the mentally retarded person with those populations who are in legal custody and segregated from society as a result of their own actions, it is a gross injustice against mentally retarded persons who are residing in state facilities because of their intensive clinical needs,

WHEREAS, the New York State Association for Retarded Children believes that it must as an organization established to advocate for the needs of the mentally retarded take this strong position against co-location on behalf of the mentally retarded who can not speak for themselves,

THEREFORE, we urge the Governor and the Legislature as well as all the citizens of New York State to rethink this policy which disregards the rights and safety of mentally retarded persons.

NYSARC's new home named

A resolution to name NYSARC's new administrative office in Delmar the Joseph T. Weingold Building was passed unanimously at the Convention.

The reality is continuous proving

EXCERPTED FROM
REPORT TO THE BOARD OF
GOVERNORS

This past year, although often times frustrating, was indeed exciting. And overall, although we did not accomplish all of our goals, we are beginning to move and react in the manner in which our Association has always been viewed — advocates for mentally retarded persons.

Although there has been much discussion concerning the New York State ARC and the direction it is taking, I feel that with all of the changes we are only reinforcing the philosophy and objectives that have been so clearly stated throughout the history of our Association. Assisting our Chapters with technical assistance, developing positive relationships with Governmental Agencies, and approaching the Legislature and Governor's Office in a positive, but direct manner, only in my opinion, strengthens the role of the parents and reinforces the basic principle of our Constitution and By-Laws. The volunteers of our organization, parents and nonparents alike, who spent countless hours over this past year to assure that our Association will continue to prosper, and more importantly, to provide services to the retarded, can never be thanked enough. Their collective wisdom, advice and commitment keeps this Association headed in the proper perspective. It has indeed been an exciting first year for me as the Executive Director of the New York State ARC. It has given me an opportunity to visit our State and to see many of our programs that our Chapters are operating. It has been often times frustrating but more times exciting.

It is obviously hard for me to be objective. I feel our Association is a little bit stronger programmatically, financially and philosophically than a year ago. If I have contributed in part to that impression, then I feel indebted to the many hundreds of individuals who I have rapidly become to realize makes this Association what it is.

I am overall pleased with the direction and development that our Association is taking. I truly sense that our Chapters are cooperating and have a stronger understanding of the role and importance of our State Organization. I sincerely hope that we are beginning to give our parents the tools and knowledge necessary to insure that their Association survives and to continue to provide for their children the quality of life that all of us know is the right for the mentally retarded of New York State. This has been indeed an exciting year but much of what has been accomplished has laid the groundwork for our future.

Mark N. Brandt
Executive Director
NYSARC

LETTERS to the EDITOR

Dear Editor:

In recent weeks, the islands in the Caribbean have again been in the headlines and their significance and status is becoming even more prominent. In March, 1983, I had the opportunity to visit the island of Jamaica for two weeks, sent there by the federal government, to serve as a consultant, to help establish and develop programs for the handicapped. This trip was sponsored by the national organization called "Partners", which links up different areas of the United States with regions in Central and South America, to provide technical assistance and aid to these under-developed areas.

The island of Jamaica itself, is indeed a "tropical paradise". It is the third largest island in the Caribbean, just South of Cuba, and rises from lovely beaches to lofty green clad mountains, with a climate that is a pleasant 80 degrees to 85 degrees year round on the coastal areas. The island is a little smaller than the state of Connecticut, and has a population of about 2,000,000 people.

While there, I stayed in Kingston, at the home of Dr. Molly Thornburn, one of the few pediatricians on the island, and the chairperson of the Caribbean Institute on Mental Retardation. She is a very dynamic individual and has been the impetus for the development of programs for the retarded and handicapped in that region. She operates an Early Stimulation Project in Kingston and in Spanish Town, and I had the opportunity to spend several days working with her there. This program is small and the need is great. Mothers, usually in their teens, coming from the city and mountain areas, would bring their infants for a diagnosis and assessment, and would receive instructions as to a few simple things that they could do for their child, usually in relation to nutrition and basic health care. Many of these young mothers were illiterate, as there is no compulsory education on the island, and few educational opportunities outside of the city area. There is little or no follow-up service unless the mother is willing to return in six months for a follow-up visit. An adapted Portage Checklist was completed on each infant by an Aide, usually a high school graduate who had received training by Dr. Thornburn, and receives 25 dollars a week for her services. This is the only infant program on the island and funds to maintain it are very meager.

I also spent several days at the School of Hope, operated by the Jamaican Association For the Mentally Retarded (JARC). The program is located on a hill outside of the city of Kingston and the school consisted of several large rooms, fairly bare of equipment or supplies, with classes of from ten to fifty children to one teacher. There is no transportation available, so children must walk, often many miles a day to attend. The JARC also operates a small farm where they are able to raise some food to feed the students, although the two days I visited there, I observed children eating thin cracker like wafers and flavored water for their lunch. The staff expressed concern about the lack of supplies as even the basic needs of books, pencils and writing paper were not available.

The JARC also operates a small group home for children on the grounds of the school. Here again, the building contained few pieces of furniture and little else.

In talking to individuals there, I learned that the problems the JARC were facing were similar to those of many of our

Chapters such as obtaining people to serve on their Board, the relationship of the Executive Director and the Board, differences of opinion in setting priorities and directions for the agency and funding issues.

However, the problems the JARC are facing for even survival are far more intense. The mentally retarded and the physically handicapped in Jamaica have no legal rights to services, or even an education since as was mentioned before, there is not even any compulsory education for any children there. The services that are available are few and outside of those in the Kingston area, are non-existent. Professional staff are paid by the government, since all programs and services are operated by the government, and they receive a very small salary as well as being assigned by the government to where they must work. For example, there are only three Physical Therapists on the entire island, and the one I spoke to was paid \$600.00 per month, which is not much to live on in a country where a dozen of eggs costs \$2.50, a 13 inch TV costs \$900.00 and a 1975 automobile sells for \$10,000.00.

I also had the opportunity to meet with the Minister of Social Services of the island, the branch of the government responsible for the programs for the handicapped, and we discussed the problems involved in attempting to provide services. In a country where the majority of the population is uneducated and lives in extreme poverty, with an extremely high rate of unemployment and little opportunity of ever being employed, the problems in providing services to the general population are currently overwhelming, and as a result, the needs of the handicapped have a very low priority, and the prospect of even their basic needs being met in the near future remains dim.

Yet, there is a bright side too. Through the dedication and efforts of individuals such as Dr. Thornburn and the degree of caring, I observed by the staff in the various places I visited, some needs will be met, and a greater degree of awareness of these needs will be created. While I was there, I assisted in writing a grant for a Parent Training Program and for a Resource Center, and subsequently both grants have been funded and are in the process of being implemented. I spoke to a class of students training to be teachers at the Mico College in Kingston and their interest and concern for the handicapped was most impressive and hopefully these young people can make a contribution to the field as they pursue their future careers.

The extremes of wealth and severe poverty, of a few excellent services and the absolute lack of services on most of the island, the few well educated and the vast number of illiterate, have left a lasting impression and have certainly given me a greater understanding of the problems of the underdeveloped countries. Coming from New York State where children's basic needs are met, where children and parents have rights under the law, and where even though we have needs for expanded services, at the same time we are discussing using funds for computers and technology for our children, and then going to a country where the handicapped are ignored and often left to die, really changes one's perspective of the challenges that lie before us, and the need for us to strengthen our efforts on behalf of all the mentally retarded and their families.

— Shirley Reynolds
Past Secretary NYSARC

Dear Editor:

Sometimes no news is good news. During the past ten years many ARC Chapters around the state have made "news" when they attempted to develop new community residences and encountered community opposition. The press was quick to pick-up on these stories, often adding fuel to the fire. Many parents, ARC staff and other advocates longed for the day when a community residence could be developed without the community opposition and related negative press coverage. Unfortunately, a community residence opening without neighborhood opposition is not as newsworthy as a major community confrontation, from the point of view of many journalists. However, we think OCV readers will still be pleased to hear of the experiences of one of our Chapters, which hopefully indicates a new attitude of community acceptance.

Like many other ARC's, the Rensselaer County Chapter has experienced its share of community opposition to residence projects in the past. However, during 1983 the Rensselaer ARC developed three new residences without major community opposition.

The first residence, at 304 Hoosick Street in Troy, was opened early in the year. Hearing news of the planned opening, one neighbor called members of the City Council to ask about the project. He received the same answer from both Republicans and Democrats on the Council; that the ARC had run a number of similar residences in the City for a number of years with no loss of property values and no problems with the neighbors. Since the Troy City Council has a reputation for disagreeing over even trivial issues, this neighbor was amazed to find agreement over the new group home. His calls to the City Council members left him convinced that he had nothing to fear as a result of the development of the residence. There was no opposition to the project from the neighborhood.

During the summer the ARC moved into a second residence, at 1 107th Street in North Troy. When letters were sent from the ARC to residents of the neighborhood, ARC staff braced for the usual onslaught of calls, petitions, etc. There were none. Perhaps because there have been two very successful community residences in other parts of North Troy; perhaps because two families in the neighborhood have mentally retarded children; or perhaps because people are, in general, more aware of the fact that community residences do not pose a threat to their property values; the opposition never appeared.

Shortly after Labor Day, the Rensselaer ARC broke ground for a new HUD 202 residence on Oakwood Avenue in Troy. Again, there was no opposition. This time there did appear to be a logical explanation. For the past ten years, two churches in the community, St. Bonaventure's Roman Catholic Church and Our Saviors Lutheran Church, have held a joint Thanksgiving Day service with the proceeds going to the ARC. In addition, many members of these churches have become involved as volunteers with the ARC. Both churches have hosted the ARC's adult evening social programs on numerous occasions. With this degree of involvement, it is easy to see why a community residence would be welcome in the neighborhood.

These stories are not dramatic or earth shaking. Indeed, many editors would not even consider them newsworthy. We think OCV readers might disagree.

— Jim Flanigan,
Executive Director

December, 1983

Dear Editor:

Commissioner Arthur Webb's exhortation to the State Convention, October 22, 1983, that we learn to "do more with less" was an insult to our intelligence. Furthermore, it showed an inexcusable and deplorable lack of understanding of how community services are delivered to the mentally retarded.

Apparently, the obscene imbalance between the state budget for the institutionalized population and those in the community does not disturb the Commissioner at all.

Long ago we had a saying, now apt to the "do more with less" situation: it is, "Don't teach your grandmother how to suck eggs."

Oh, Lord, how much longer will we have to suffer this kind of nonsense!

Sincerely yours,
Joseph T. Weingold

Going somewhere? Help organized

A NEW GUIDE TO TRAVEL FOR THE HANDICAPPED: "Access to the World", a new book by Louise Weiss on worldwide travel for the handicapped, contains a wealth of information for the physically disabled person wishing to travel anywhere on the globe.

It is designed for the non-ambulatory, for the speech and sight-impaired, and the aged and all others with restricted mobility and covers transportation by air, ship, rail, bus and auto. The book lists hotels and motels with special accommodations for the handicapped, gives advice on how to find out about special tours, how to make travel arrangements, what to take with you and what to do when you get where you're going. Additional health and travel tips are included. The book is available at \$14.95 plus \$2 for postage and handling from: The Complete Traveller, 199 Madison Avenue, New York, NY 10016.

Four letter words in the dictionary of the disabled

Four letter words are offensive. So are some of the words used in referring to people with disabilities.

In United Cerebral Palsy, we're concerned about some of the inappropriate words used to describe people who have cerebral palsy.

Here are some of the "No-No's" pertaining to cerebral palsy. The other ones we're sure you know.

AFFLICTED — Very negative and a definite downer! Person who has or is affected by cerebral palsy is much better!

CRIPPLED OR CRIPPLER — This paints a mental picture no one would look at.

DISEASE — Heavens no! Cerebral Palsy is NOT a disease. People with cerebral palsy are as healthy as anybody else. Better to say condition.

POOR — Cerebral palsy has nothing to do with how wealthy one is. Love and self-esteem are priceless qualities. One's character determines the richness in one's life.

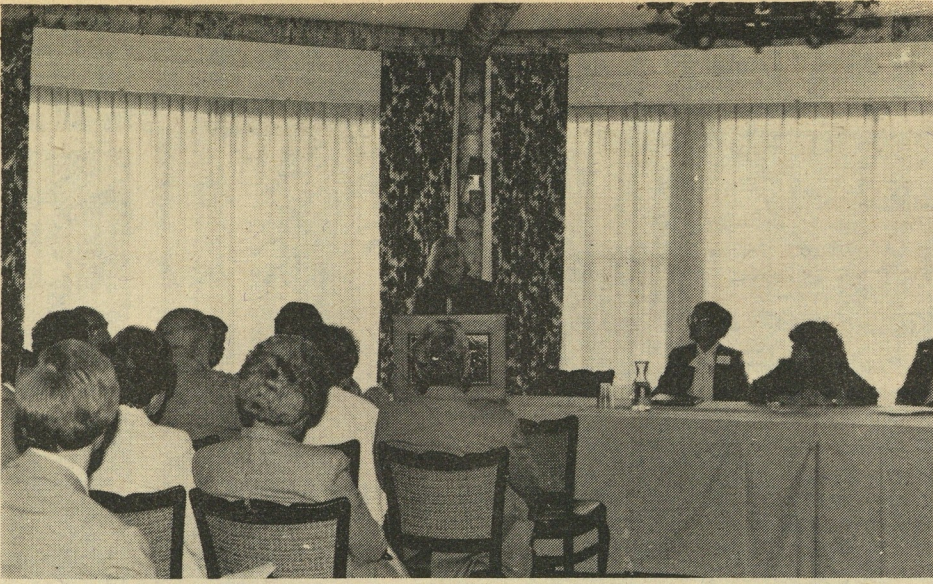
UNFORTUNATE — What's unfortunate is that this word is part of our vocabulary. Don't offend with this one.

VICTIM — A person with cerebral palsy was neither sabotaged nor necessarily in a plane, train or car crash. There's no way to rephrase this turkey.

We hope that you will keep our impromptu dictionary for future reference and that as our brethren in the media delete these "swear words".

It's one of those challenges we hope you'll tackle with pride and determination.

— UCP State



Karin Burgess, Past Executive Director from Cortland Chapter speaks on guardianship issues at convention.

Orange County ARC guardianship assist

The mentally retarded are not deemed incompetent.

The phrase is "Incapable of self-management",

implying, "I need help to manage my affairs"

On a Thursday afternoon, a young woman fell down the stairs and broke her hip. It wasn't until the following Monday morning that she was wheeled into surgery to have the bone reset.

The woman was over 18, and therefore legally considered an adult. Her parents no longer qualified as her guardians. However, she also was mentally retarded, and thus deemed incapable of authorizing her own medical treatment.

What her parents didn't know was that after her 18th birthday, they had to either register with the Surrogate Court as her legal guardians or appoint someone else to fill that role.

Her's wasn't a life-or-death situation. (In that case, the hospital would have immediately administered care.) But in order to perform surgery, the doctors had to obtain a court order, which took until Friday afternoon. By that time, the health center was closed for the weekend.

This kind of predicament and others have caused concern among staff members at the Sullivan County branch of the Association for Retarded Children (ARC).

"Most people are pretty much uninformed in the whole area of guardianship for mentally retarded people," said Martha Morgan, quality assurance specialist at the South Fallsburg ARC center, where 110 mentally retarded persons currently reside.

Ms. Morgan has found, based on comments from parents who have sought legal advice on guardianship, that many attorneys lack knowledge on the subject.

"Attorneys either turn them away and say, 'You don't need it' or 'I don't know anything about it, let me research it.' " They are unaware that parents must contact the local Surrogate Court to secure guardianship, she said.

"The phrase is 'incapable of self-management,' implying, 'I need help to manage my affairs,' " she explained.

Ms. Morgan noted ARC tries to help the mentally retarded person live independently. But many of the problems that go along with independence — inheritance taxes, large funds management and complicated medical procedures — are obviously overwhelming. Establishing a guardian — whether a parent (most commonly the case), a relative, an interested acquaintance such as a counselor, or an organization such as ARC — will assure the retarded person's rights and generally enhance his welfare, she said.

Ms. Morgan is trying to establish a program through which a mentally retarded adult would undergo a series of

evaluations with psychologists or other therapists. Professionals would then decide whether the person was capable of making legal, medical and other personal decisions up to a certain level. The person would be provided with a letter indicating the level competency, she said.

"As much as possible, we want the client to be independent, to insure his rights and to develop the quality of life, and to do as much as he can for himself. What he can't do for himself completely, that's when we feel there's a definite need for a guardian," she said.

When an American citizen turns 18, he becomes his own guardian by law. But "an 18-year-old person with a 30 IQ" needs a guardian to guide and represent him on legal and other issues, Ms. Morgan said.

One of the major problem areas involves medical procedures. If a retarded person is admitted to a hospital for surgery, the hospital will rarely accept that person's authorization, she said.

"More often than not, if the parent is involved, they (hospital personnel) will take the parent's authorization even though legally they're not supposed to," she explained. "The general theory is they'll do this because if anything should go wrong, the only people who would sue would be the parents.

"We get hung up with a lot of our residents in situations where there is no parent involved, so there is no one to sign for the client," she added. In these cases, a non-related person assigned as guardian would fill the bill, she explained.

Ms. Morgan clarifies the common confusion between the guardianship roles for a mentally ill person and for one who is mentally retarded.

"A mentally ill person is deemed incompetent, and... most of his legal rights are removed. With a mentally retarded person, that does not happen. They still have a right to vote; they still have a right to get a driver's license. They're not deemed incompetent.

Mentally retarded need guardians

At a recent seminar on the guardianship issue sponsored by ARC, George Gerstheimer of Highland Mills, whose 34-year-old son Paul is retarded, called the mentally retarded "a forgotten population." Gerstheimer, who is chairman of the Orange County ARC Guardianship Committee, feels that guardians provide their wards with an important link with the outside world. He also feels

Guardianship-an enlarged commitment

The NYSARC Guardianship Program is progressing at a stable rate of growth. It has matured to the point of providing a necessary and viable program for this Association. The Committee members are actively involved in speaking engagements throughout the State and through their involvement, information will be imparted to many of our parent members. Intent of the Committee, is to keep parents apprised of the progress and any changes taking place in addition to assisting them in the long-range planning of their children's future happiness and protection.

The Committee adopted a program of quality assurance and will begin implementing it in the near future.

NYSARC has 524 Guardianship applications on file. Of these, 54 are in the process of review and approval, and an additional 95 have been approved but are awaiting court orders. Fifty of the 524 total applications on file have been withdrawn.

In 325 cases, court orders have been granted, and NYSARC is now acting as Full Guardian to 23, Standby Guardian to 149, 1st Alternate Standby Guardian to 82, Second Alternate Standby Guardian to 38,

guardians can promote self-sufficiency by helping the retarded person plan a vacation or deal with housing problems.

Gerstheimer thinks it's vitally important that Paul cultivate relationships with people to whom he is not related. In fact, he encourages his son's independence, and visits him about once every two weeks at his apartment in Woodbourne, a 60-mile drive from his home in Highland Mills.

He also encourages people other than parents and relatives to consider becoming a retarded adult's guardian and friend. "It can be a very rewarding experience," he said.

"Some think a guardian restricts the rights of the retarded individual. Rather it's a protective sort of thing to keep them from being abused or neglected," he said.

— By Holly Johnson,
Staff Writer
Times Herald Record
So. Fallsburg, NY

Third Alternate Standby Guardian to 17, Fourth Alternate Standby Guardian to 6, Fifth Alternate Standby Guardian to 7, Sixth Alternate Standby Guardian to 2, and Seventh Alternate Standby guardian to 1.

MEDICAL ASPECTS

The issue of executing medical consents without court orders is extremely troublesome at this time. This is a concern that the Committee will formulate a policy for by addressing the Executive Committee of the Surrogate's Association in the 1984 Session of the New York State Legislature.

A Sub-Committee has been appointed and charged with assisting Developmental Center Chapters in providing guardianship services. This Sub-Committee, chaired by Committee member Paul Dhalles, will probably report on this issue within the next six months.

Jerome Ness
Chairperson

Burn out- the advocates disease

TEN EASILY SPOTTED SIGNS OF STRESSFUL BEHAVIOR

- Moving, eating or walking rapidly.
- Hurrying the ends of sentences.
- Impatience.
- Feeling guilty about relaxation.
- Thinking about work while vacationing.
- Doing several things at once; e.g. shaving and driving.
- Trying to increase work over ever-shorter time periods.
- Not listening to the opinions of others.
- Acquiring objects rather than enjoying them.
- Relating success to time; i.e., speed is everything.

Adapted from the book,
"Type A Behavior
and Your Heart"
By Drs. Meyer Friedman
and Ray H. Rosenman

Our Children's Voice

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Advice to parents on surgery

If your doctor has suggested surgery it is fair to assume that this is what he or she believes is the best course of action. In order to make the necessary decisions regarding surgery, you will need to ask the kinds of questions that will give you sufficient information. You may also wish to get a second opinion. You will need clear information:

- to decide whether to give consent for surgery;
- to clarify your expectations and feelings;
- to provide support for your child;
- to make appropriate plans for home, school, work, and family.

PURPOSE

What is the purpose of the surgery? Is it to correct a problem? Is it to help some part of your child's body develop, work or look better? Or is it to prevent something from happening that could cause a problem in the future?

PROCEDURE

What will be done during the surgery? Will something be removed, added or changed? (Are you clear about the body parts or system being discussed?) Would a diagram or other information help?)

SUCCESS OF SURGERY

For some types of surgery success can be determined immediately; for others it may take a longer period of time. Clarify with your doctor the anticipated outcomes and how and when success will be measured.

RISKS OF SURGERY

What kinds of risks are associated with this type of operation? How often do they occur?

ALTERNATIVES

Are there any alternatives or is this the only solution that is being recommended? Are there any non-surgical methods of treating this problem — medications, therapy, other? Are they done in this hospital or in other parts of this country? The world? If this is a major operation that is recommended are there any other less drastic surgical procedures done here or elsewhere that might benefit your child instead? The particular recommendation for surgery is likely to be based on your doctor's priorities and expectations for your child. If you don't already know, this may be an opportunity to learn what these are and see whether they are similar to or different from your own.

FUTURE ALTERNATIVES

Are there any methods of treatment or other surgical procedures which are still in experimental stages? How likely is it that one of these might benefit your child? How long will it be before this procedure or treatment can be evaluated and is it feasible to wait until then?

QUESTIONS TO ASK IF SURGERY IS NOT DONE

What does your doctor believe would happen if the surgery he or she is recommending were not done? Do the risks outweigh the benefits?

When does your doctor feel this surgery should be done? Why? Could it be put off if there were a good reason? For how long? Is your child at an age or stage when surgery would be very disruptive? Are there any other things happening in your child's life which would make one time better or worse than another (school, vacation, other)? Are there any times that would be better or worse for your family?

SORTING OUT YOUR OWN FEELINGS

What is your gut reaction to the surgery? Is the problem one you have already recognized or does the recommendation for surgery come as a complete surprise? Have you discussed this with your doctor? Do you feel the information you have been given is adequate and does the course of treatment seem reasonable?

Do you feel that you and your doctor are in agreement about the goals and expectations for your child?

Do you have someone — friend or professional — with whom you can discuss your own feelings?

YOUR CHILD'S ROLE IN THE DECISION

Is the decision about surgery yours to make? To what extent can and should your child be involved? (The legal age for consent in most states is 18 years. However, many hospitals require consent from a younger child in addition to parental consent.)

SECOND OPINIONS

In many instances you will want to have another physician evaluate your child. There are different methods, opinions and philosophies, even among professionals. Getting a second opinion does not mean lack of trust but it is true some doctors are more comfortable with this than others. You may wish to assure your doctor that getting another opinion will give you the confidence you need to decide this important issue for your child.

You will want to choose someone whose medical specialty covers the type of problem your child has. You may wish to know whether this person typically sees children as patients and what experience he or she has had with your child's particular method of treatment.

For suggestions you may ask the physician recommending surgery, your pediatrician or other professional who knows you well, other parents with experience, hospitals or your local medical society.

Be sure to say that this is a second opinion. There may be test results, X-rays, or other information needed from your original physician. For comparison do ask the same questions of any doctors you consult.

TYPES OF SURGERY

Surgery occurs in one of two circumstances, either **emergency** or **elective**.

Elective: Elective surgical procedures can be planned ahead. Obviously you will have a better chance of understanding the procedures and any alternatives you may have. And you will have more time to prepare yourself and your child. Although elective implies some choice, sometimes the reality is that there is no other option.

Emergency: In an emergency things usually happen very fast and you may not have time to ask the questions or prepare yourself and your child the way you would like. Hospital personnel usually make every effort to answer your questions but obviously time can be an important factor. Also, emotionally it can be a difficult time for you and your child and it may be hard to organize your thoughts. All any of us can do is to try our best and have a certain amount of trust in the professionals handling the situation.

Special Situations: If your child has a chronic disability you may want to know if there are certain surgical procedures or emergencies which are likely to occur. Many of us feel better if we have some understanding or knowledge of what lies ahead. It may help us to know how serious something is, how much room for discussion there is or what possible actions we may take.

— From Parent-Professional Communication Group



President's Message

Two years ago, we collectively made a hard decision to change our professional leadership, to rethink and possibly rearrange our priorities and goals, while at the same time to maintain and strengthen the original objectives and philosophy which has made our Association effective and meaningful to the parents and friends of the mentally retarded and, most importantly, to those we serve.

This has been a year of great change for all of us. Not only have we changed our address from New York City to the Albany area, not only have we purchased our Organization's headquarters, not only have we restructured and redefined our staff positions, but we have taken the important initial steps in bringing about a change in attitude towards State ARC.

The attitudinal change has two important parts. The first is our own attitude towards our Organization. . . It appears that over the past several years, we have been requesting, and in some instances, demanding our Chapters to be responsible while our State Organization, while growing in scope and responsibility, was not in many aspects keeping pace with our Chapters. It is my feeling that in order to assure that our Chapters are complying with our procedures, our own Organization has to become a model of responsible corporate management. With respect to this, I am pleased to report that the financial stability of our Organization is stronger today than it was a year ago. . .

The second part of this attitudinal change is concerned with how others

perceive us. I am confident in reporting to you that through our actions and the approach and determination of our Executive Director and the integrity and professional capability of our State Association staff, the Office of Mental Retardation, the Commission on Quality of Care and other regulatory agencies are turning to our State Association when problems arise, rather than either attacking our Chapters individually or embarrassing us publicly.

I believe the attitude being shown by all these groups is an indication of the correctness of the path we have chosen. Our collective strength is being recognized and respected; and as a result, I am sure the quality of life for the mentally retarded throughout our State will be enhanced.

I am confident that we are meeting the challenges presented, that we have grown from this experience and will become a stronger Organization, more courageous and determined in not only our approach to the problems presented us but in our ability to intelligently, compassionately, legally and morally properly resolve the issues. . . My only plea to all our members, is that all of us, the volunteers, the parents and non-parents alike, renew our dedication to our purpose and take a more active role in our Association.

Although there is much that remains to be done, I am confident that our Association has never been as strong, our commitment never as determined, and the support we are now experiencing as intense as it is today.

Irene L. Platt, Esq.

Developmental Centers concerns highlighted at convention

The New York State Association for Retarded Children is strongly opposed to the policy of decreasing staff ratios in the Developmental Centers, and is very concerned about the impact of this policy on the Community based programs for the mentally retarded in New York State.

The ARC has long expressed concerns about whether the 1.78 to 1 staff: client ratio proposed by OMR-DD is actually sufficient to meet client needs. We now believe that this ratio is in jeopardy of being lowered to a ratio that will endanger the health and safety of the mentally retarded people in both the institutions and in the community. We are also seriously concerned that any further reductions in State staff will cause an increase in the returns of many clients to the institutions due to insufficient community support systems.

The New York State Association for Retarded Children is opposed not only to any reduction in the direct care staff to client ratio but also to any reduction in administrative, clinical and support staff

both in the facilities and in the community. The lack of sufficient case management and program development staff in the State sector will place an overwhelming burden on the voluntary sector, concerned with community programs, which is already struggling to provide basic program services to the mentally retarded.

We believe that, unless the current trend toward staff decreases is reversed, we will see a return to situations such as occurred at Willowbrook, in a few short years, namely custodial care.

NYSARC believes that the Governor, the New York State Legislature, and the OMR-DD has an obligation to maintain and improve quality services to the mentally retarded who have been short - changed for so many years. We all have a moral commitment to protect the civil rights of this segment of our society, and NYSARC is determined that the commitment cannot be abandoned because of economic expediency.

— Bernice Volaski, Chairperson Developmental Centers Committee

The identity barrier

ID cards for non drivers

A bill authorizing issuance of an identification card for non-drivers has been signed into law, according to the bill's sponsor, State Senator John E. Flynn. The enactment into law caps a seven year effort initiated by Senator Flynn when he was Chairman of the Senate Select Committee on Problems of the Aging. It empowers the Commissioner of Motor Vehicles to issue the I.D. card, on request, to all those over 18 years of age. The cards will also be available from County clerks. Senator Flynn stated, "Those individuals who do not drive are unable to provide the most universally accepted form of personal identification in New York — a driver's license."

Today more than ever, a driver's license has become a standard form of identification for persons wishing to cash checks, pay by check, receive credit and borrow materials. Persons with disabilities and the elderly have been especially affected by this omission and are often subjected to unnecessary scrutiny and rejection. As Chairman of the Senate Select Committee on the Disabled, I am dedicated to guaranteeing that New York provide every opportunity for the disabled to pursue and benefit from all rights and services that will lead to a satisfactory barrier-free life-style."

The law is scheduled to take effect June 4, 1984.

Psychological slavery exposed

Neighbors say two 'slaves' were friendly but helpless

By John Holusha

— Reprinted by permission of The New York Times

CHELSEA, MICH., OCT. 28 — Some Chelsea residents say that two mentally retarded men, who the Federal Government says, were kept for more than 10 years as slaves on a farm near here were familiar figures in the community and did not appear to have been physically restrained. But others say they believe the men were held in at least psychological bondage.

"They were driving up and down the road all the time, either on a tractor or in a pick-up truck," said James V. Fowler, a lawyer whose house is adjacent to the Kozminski farm, on which the men lived. "They worked long hours, but they were always friendly, waving and saying hello as they went by."

In October, 1983, Ike Kozminski, 60 years old, his wife, Margarethe, 54, and their son John, 30, were arrested and charged by the United States Attorney's Office with holding the men in "involuntary servitude by compelling their labor and preventing them from leaving" their employment. The men, Robert A. Fulmer, 57, and Louis Molitoris, 59, were taken from the farm in August and resettled in foster care.

The Government's complaint said both men had been physically forced to return to the Kozminski farm when they attempted to leave, but others say the control was more mental than physical. "Those boys were mentally deficient and they were scared," said a neighboring farmer, who spoke on condition that he not be identified. "They were afraid to run away and at least there they had a roof over their heads."

NO WAGES PAID, THEY SAY

According to a statement by James Riley, an agent of the Federal Bureau of Investigation, Mr. Fulmer had been on the farm since 1967 and Mr. Molitoris since 1972. In that time, Mr. Riley's statement said, the men said they had been paid no wages except \$10 at Christmas and Easter and had been forced to live in a trailer without heat, running water or toilet facilities.

The men were also said to have been denied medical and dental treatment and a former employee of the family said Ike Kozminski had told him to beat or kick the men if necessary to make them work.

Repeated efforts to reach the Kozminskis for comment were unsuccessful.

The senior Mr. Kozminski was described by neighbors and members of this rural community as a loner with a penchant for cutting corners in an effort to make a success of the two farms he owns in this area. The farms are three-quarters of a mile apart.

"He wasn't much of a dairy farmer," said Jerry Neese, an official of the local branch of the Michigan Livestock Exchange. "The cattle he brought in here to sell were sickly and thin and he had trouble selling his milk as Grade A." Mr. Neese added that when reports emerged

last August that a farmer in the area might be charged with slavery, "there wasn't much doubt in people's minds" that it would be Mr. Kozminski.

'HOBBY FARMERS' ARRIVING

This area of gently rolling countryside, 15 miles west of Ann Arbor and the University of Michigan campus, is in the midst of gradual social change. Century-old family farms are interspersed with "hobby farms" and modern homes of office workers who want to live in the country.

The influx of these homeowners has driven up land prices and made it difficult for newer farmers to meet land payments and operate profitably, long-time residents say.

Mr. Kozminski, an immigrant from Poland who neighbors said was formerly a barber in Ann Arbor, evidently made little effort to mingle with his neighbors.

Despite the presence of a large house on the main farm — the elder Kozminskis home stands on the opposite side of Peckins Road from the farm buildings — the complaint said the men were housed in a trailer that was so filthy that it was condemned by the Washtenaw County Health Department as unfit for human habitation. The trailer can no longer be seen on the farm, and neighbors report that it was dragged into an open field and burned shortly after the condemnation.

DEPENDENT FOR MEALS, THEY SAY

The two men were evidently dependent on the Kozminskis for all their needs. "One day when Margarethe was away, Bob said he was upset because he didn't think he was going to be fed," Lynn Fowler, the next-door neighbor, said. Mrs. Fowler also said Mr. Fulmer told her he had not been taken to a hospital when he severed a thumb in an accident. "He said, 'They took care of me,'" Mrs. Fowler said.

According to the complaint, all three Kozminskis told neighbors the two men were in their legal custody.

Leonard Gilman, the United States Attorney for the Eastern District of Michigan said the case of the two men had been brought to his attention by Washtenaw County officials. He said the Kozminskis were charged by Federal rather than state or local officials "because we have a statute that is right on point." "There is no state statute in Michigan that prohibits slavery," he said. Federal law prohibits involuntary servitude.

Mr. Gilman said the Kozminskis had been arrested because there were indications that the parents were planning to leave the country. Neighbors reported that the Kozminski dairy herd had been sold after the two men were removed from the farm in August and that all the machinery on the two farms was up for sale. But Mr. Gilman said the Kozminskis had turned their passports in to the authorities after the arrests.

From the Executive Director's Desk

— Marc N. Brandt

This edition of Our Children's Voice highlights the 1983 Annual Convention of the New York State ARC recently held at Lake Placid, New York. I am sure all of those in attendance at our Convention join our State organization in sincerely thanking the Essex County Chapter for being the perfect hosts. The hotel, meals, and meeting rooms were professionally handled and added to the success of the convention. The Board of Governor meetings as well as our General Assembly ran smoothly and were extremely well attended. Our banquet had the newly appointed Commissioner of the Office of Mental Retardation, Mr. Arthur Webb, as its guest speaker, and our Niagara Chapter accepted the Employer of the Year Award on behalf of our Association, given to Ponderosa Steak House in Niagara Falls, New York. Our workshops were stimulating and offered a variety of professional issues of concern to those who are mentally retarded in New York State.

All in all, our convention for 1983 was a productive success. But looking back at our convention, accomplishment begins not during the convention, but when the convention is over. No other highlight of this year's annual convention is perhaps more important than the 1984 Legislative Program and Platform adopted by our Association at its General Assembly Meeting. This year, the Association has elected to pass legislation in a number of key areas which affect the lives of those who are mentally retarded. Although elsewhere highlighted in this issue, the importance of our Legislative Platform needs to be reinforced. This year, the Association is planning to have sponsored a bill which prohibits the State of New York from the co-location of developmental centers with correctional facilities. The Association will also attempt to sponsor legislation which forces the State Education Department and the New York State Office of Vocational Rehabilitation to follow the mandates of the original

Sheltered Employment Program (SEP) rather than the restrictive regulations which, in our opinion, are contrary to the original law for sheltered employment. We will, again, attempt to work cooperatively with other groups in education for children who are developmentally disabled. Our organization will also be attempting to sponsor a bill to extend the operation of our racing tracks one day so as to provide the proceeds to not-for-profit organizations such as the New York State ARC. And finally, a Bill of Rights will be proposed for the rights of persons who are in community residences. It is sad to note that in 1983 such a Bill which reaffirms the rights of individuals who are mentally retarded must be presented as a law.

Our Legislative Platform is simple yet concerned with the quality of life of mentally retarded individuals. We will, during the coming weeks, be calling upon all of our chapters to assist us in working towards the enactment and adoption of the 1984 Legislative Platform. As bills receive sponsorship and are presented to both the Assembly and the Senate of New York State, we must cooperatively work together to assure that they will be presented to the Governor for his review and ultimately for his signature.

During the 1984 Legislative Session, we will once again be calling upon our Chapters to visit their local Assemblymen and State Senators in Albany to review with them our Legislative Platform. We urge all of our Chapters to join with us this year in the working for the successful enactment of our Legislative Platform. We, at the State Association, feel confident that while our legislative goals are ambitious, they represent the needs of those who are mentally retarded in New York State and represent the thinking of our Association. Your Chapter's participation this year is not only being requested but is being considered a responsibility which must not be taken lightly.

Willowbrook update

The Supreme Court let stand in October, a ruling that New York State officials may ease overcrowding at the former Willowbrook Developmental Center, a facility for the mentally retarded, at a slower pace than previously ordered.

The order to empty the center came as a result of a 1972 lawsuit challenging overcrowding and other inhumane conditions.

The suit was settled in 1975 when a court ordered the residents be relocated to community facilities of up to 15 beds for mildly retarded adults, and no more than 10 beds for more severely retarded adults.

Unable to meet the April 30, 1981, deadline, New York officials sought to modify the order after failing to open the required number of community facilities.

Between 1979 and 1982, they were able to open only 131 of 262 facilities planned for New York City. In 1982, nearly 1,400 patients remained in the Staten Island center.

The state ran into the tight housing market in New York City as well as significant community residence. Officials also said federal and state requirements for housing for retarded patients frustrated the acquisition of many facilities.

They urged a federal court judge to allow the facilities to hold up to 50 patients.

However, the district court judge held that the Willowbrook patients would be better off in small community facilities. He ruled that many of the deplorable conditions — unsanitary conditions, lack of proper clothing and staff, and absence of rehabilitative programs existed in the 50-bed facilities.

That ruling was reversed by the 2nd U.S. Circuit Court of Appeals, which held the primary objective of the 1975 judgment was to empty Willowbrook.

The court described state officials' evidence as "unquestionably establishing" that the primary purpose could not be realized unless the order was modified to allow 50-person facilities.

The New York Civil Liberties Union appealed the case to the Supreme Court.

Has your chapter seen best boy yet?

It can be your Fund Raiser. Inquire from IFEX Films, 159 West 53rd Street, New York, New York 10019.

After 13 years-baby justice

A 13 year-old Brooklyn girl who was born mentally and physically retarded won a \$7.4 million settlement of her medical-malpractice lawsuit against a Brooklyn hospital.

The settlement with Long Island College Hospital was approved by Brooklyn supreme Court Justice Frank Composto.

A financially comfortable future was thus assured for Leila Revels, who lives on

welfare with her family at 124 Bush Street in the Red Hook Projects.

On July 3, 1970, Carolyn Revels, 40, went to Long Island College Hospital with a burst amniotic sac. But doctors there said nothing was wrong and sent her home.

Because of the burst sac, the baby was not getting enough oxygen and should have been delivered by Caesarean section, the Court found.

Dr. Robert Guthrie honored by NYSARC

Dr. Robert Guthrie was given an Award for Excellence for his "Service, Research and Leadership in the field of Mental Retardation," at ceremonies of the Association on October 22, 1983.

In making the Award, Joan Edwards said, "Dr. Guthrie, this Award for Excellence is being given to you by N.Y.S.A.R.C. on behalf of all the children and their families throughout the world, whose lives have been made more meaningful due to your commitment, research, and leadership. On their behalf we say, 'thank you, Dr. Guthrie,' we are proud that you are one of us."

President, Irene Platt, who asked Joan Edwards, Chairman of the Board of Governor's Committee on Prevention of Mental Retardation and Developmental Disabilities, and Coordinator of the Western New York Task Force for Prevention to present the Award, led a standing ovation with the assembled convention of delegates, parents and Board of Governors which indicated their appreciation of the outstanding contributions Dr. Guthrie has made in the improvement and quality of life for so many persons world-wide.

Dr. and Mrs. Guthrie are the parents of six children, one of whom is handicapped and lives in a community residence in Buffalo. They have been active for over 30 years in the work of this Association, locally, state-wide and nationally.

Currently, Dr. Guthrie is Professor of Pediatrics and Microbiology at SUNY, Buffalo. He is best known for his development with A. Susi of a method for detecting PKU (Phenylketonuria) in newborn infants, the early treatment of which can prevent one form of mental deficiency. Over 50 million children have been screened and thousands are living normal lives because of his research.

Less well known may be some of his work during the past 30 years which include appointments as:

Surgeon, U.S.P.H.S., Department of Experimental Biology and Medicine, National Institutes of Health, Bethesda, MD.

Professor and Chairman, Department of Bacteriology and Immunology, University of Kansas.

Assistant, Department of Chemotherapy, Sloan-Kettering Institute, Rye N.Y.

Principal Cancer Research Scientist, Roswell Park Memorial Institute, Buffalo, N.Y.

Research Associate Professor of Pediatrics, State University of New York at Buffalo, N.Y.

Visiting Professor, University of Otago Medical School, Dunedin, New Zealand.

In addition a bibliography of his published research contains over 80 topics.

Some of the awards received recently by Dr. Guthrie include:

American Association on Mental Deficiency, Science Award in 1970;

American Academy on Mental Retardation, Fifth Annual Career Research Scientist Award — 1981;

Distinguished Research Award — Association for Retarded Citizens — U.S.A.;

Pool of Bethesda Award — 1983 (honors persons who have made outstanding contributions in the field of Mental Retardation).

N.Y.S.A.R.C. wishes Dr. and Mrs. Guthrie many years of good health and continued service.

New kind of Military alert

Griffiss Air Force Base Notice to All Military:

People on Griffiss Air Force Base can help the Association for Retarded Children by saving empty bottles and glassware for recycling. Those items can be left in yellow bins at the Non-commissioned Officers Club or the Country Store.

Rome, N.Y. Sentinel



Dr. Robert Guthrie being applauded by Joan Edwards, Chairperson of the Prevention Committee for his contributions in the field of mental retardation.

The prevention committee reports

Dear Mr. and Mrs. John Q. Public:

Please consider this an open letter to each and everyone of you from the New York State Association for Retarded Children (NYSARC) Prevention Committee. We are happy to inform you that by all indicators, "Prevention of Mental Retardation and Developmental Disabilities (MR-DD) is a thing whose time has come". Prevention of MR-DD is attracting more and more attention from broader sectors of society.

The NYSARC Prevention Committee has been actively involved with prevention efforts across New York State during the past several years. This Committee has developed public service announcements, television spots, and radio shows regarding prevention. Some members served on the Governor's Conference on Children of Alcoholics. Other members have addressed issues of prevention during conferences held in Toronto, Canada, various locations in New York State, and other states.

This Committee has sponsored conferences held in New York State regarding child auto passenger safety, prevention of childhood lead poisoning, fetal alcohol effect and other issues. School districts have received practical information in the form of lectures and demonstrations of an approved curriculum developed for junior and senior high school students. School health teachers have been encouraged to use innovative methods to reach teens with the important message of good nutrition.

Articles written by this Committee have appeared in numerous journals, newspapers and periodicals.

Organizations and agencies dealing with teenage pregnancy, health related issues, community action organizations, advocates and professionals have met to determine what strategies can best be utilized to achieve the goal of this NYSARC Prevention Committee: "To lessen the incidence of Mental Retardation - Developmental Disabilities".

New York State Department of Health, through the Jobs Bill No. PL 98-8 is actively promoting programs aimed at the prevention of infant morbidity and mortality, as recommended by the Governor's Conference on Prevention of Developmental Disabilities and Infant Mortality. NYSARC Prevention Committee has been collaborating with the New York State Department of Health and wishes to publicly extend its appreciation to the dedicated staff for their guidance and cooperation.

Our major projected goal for 1983-1984 is to actively advocate for the Legislative Commission of Prevention of Mental Retardation and Developmental Disabilities. It is our hope that this could become a viable channel through which efforts toward prevention of MR-DD could be initiated.

Joan Edwards, Chairperson

The flu-Reyes connection

Reyes Syndrome is one of the top 10 killers of children under 12 but can be treated with no side effects if diagnosed early.

The Winter months are significant because most cases follow Influenza "B".

You could save a child's life by sending for a free brochure describing the symptoms by sending a self-addressed stamped envelope to:

R.S.

Box 701

Dryden, New York 13053

Gates safety alert

The Consumer Product Safety Commission has cited seven recent infant deaths in warning of entrapment and strangulation hazards with accordion-style baby gates.

The Commission said that in its opinion mesh-style baby gates are safer than the accordion versions, which have V-shaped openings along the top and diamond-shaped openings on the side.

It said in a statement that it has reports of "seven deaths and 17 near misses because of the entrapment hazard."

NYS to build centers to aid retarded and handicapped

New York State will build residential treatment centers for an additional 3,400 retarded or handicapped persons over the next three years.

Arthur Y. Webb, Jr., who is the State Commissioner of Mental Retardation and Developmental Disabilities, said the centers would provide space for "only 60 to 65 percent" of those additional persons who needed it, including a growing number of young adults who were no longer eligible for government-subsidized foster care.

Mr. Webb said the cost for each new bed was about \$35,000, or \$119 million overall, with 40 percent of the money coming from

Prevention update

Lead poison

curbs stressed

By Rosemary O'Hara
Staff Writer

SARATOGA SPRINGS — Lead poisoning control should be part of a larger network of family health services and support programs, Albany County Health Commissioner William Grattan said in October.

At a Child Lead Poisoning seminar at the Gideon Putnam Hotel, Grattan said the condition is often found in families that have a host of social, nutritional and behavioral problems. He said those problems must be addressed as children are screened and treated for lead poisoning.

Grattan said the Albany County Lead Poisoning Control Program utilizes visiting nurses and community resident health guides who visit homes where children have elevated or suspicious levels of lead in their blood.

The visiting nurses go to homes to find out how lead exposure fits into the overall picture of family life, Grattan said. The visits are designed to educate parents about how to reduce or eliminate the risk and to see what other changes can be made in the households to remove lead exposure. Environmental technicians also visit homes to find out what is causing a high level of lead exposure.

Grattan was one of seven scheduled speakers at the day-long seminar sponsored by the New York State Health Department, the Albany County Health Department and the Committee for the Prevention of Mental Retardation and Developmental Disabilities of the New York State Association for Retarded Children.

Lead poisoning can occur when a child chews or eats loose chips of lead paint or painted plaster. Lead-based paints are most often found in homes and buildings built or remodeled before 1960. Most paints today carry low levels of lead due to federal regulations. Lead can be transferred to the air and soil through traffic fumes from leaded gasoline or industries producing leaded products. And older furniture that has been coated or recoated with lead paint or lead-based stains can also be a source of poisoning.

Lead poisoning causes death in its severe form and mental retardation in its chronic low-level form. It can also cause kidney disease and blindness.

Lead enters the body through the lungs, skin and stomach and ends up mainly in the blood, brain and bones.

The best way to prevent lead poisoning, officials at the seminar said, is to remove the hazard. This can be done by using a paint scraper or putty knife to remove all loose pieces of paint, especially on windowsills or woodwork that children can easily reach. Never paint over old paint — the lead hazard will still be under the layer of new paint. Dust, fumes or paint chips must be controlled when the paint is being removed.

Federal and voluntary sources. There are now 26,000 beds provided or licensed by the state for the retarded or developmentally disabled.

Mr. Webb testified before the Assembly Subcommittee on Human Rights about "aging out", the term used by state officials to characterize problems of handicapped persons who reach the age of 21 and may no longer receive paid foster care or other assistance.

While about 1,000 persons "will be aging out" in New York over the next three years, the state's building program will provide space for only 300 of them, Mr. Webb said.



Welcoming smiles worn by staff from the host chapter, Essex County, invite conventioners to register.

Get involved urges WARC exec

A recent article in the *New York Times* entitled "Physical and Mental Disability in Newborns Doubled in Twenty-five Years," has brought the field of mental retardation to the forefront of debate in editorial columns throughout the country. In an odd way, the debates are useful simply because they bring vital issues before the public and force us to recognize the legal, moral and programmatic implications inherent in the field of mental retardation.

An editorial in response to the *Times* article submitted by Mr. Joseph A. Buonomo, National President of the Association for Retarded Citizens of the United States, brought the issue to a head. He wrote, "The evidence today indicates that at least 50 percent of the incidence of mental retardation can be prevented. Since children born with mental retardation frequently possess other handicapping conditions, prevention offers a substantial payoff not only to children and their parents but to society as well." Buonomo goes on to say that the *Times* article suggests "there is a category of children who upon birth should automatically be placed in institutions or otherwise be relegated to being the taxpayer's burden. These youngsters' potential is not so quickly and easily preordained." In his editorial, Mr. Buonomo crystalized the issues for us. Whether we are speaking of the notorious "Baby Doe" case or any newborn disability, the mandate of WARC is to provide services to handicapped individuals so they may realize their true potential in our society. All too long we have allowed our legal and medical professions to "preordain" the placement and treatment of handicapped individuals without regard for the true exploration of potential.

I would like to go beyond Mr. Buonomo's statements with regard to the fact that programs exist for the handicapped people of all ages in the country today. I would like to point out that every one of us has responsibility for every new "Baby Doe" in our society. We are responsible because ARC's or other organizations serving the handicapped must look seriously at the way we publicize services, and educate the general public to the availability of help. There are people in our society who still believe that the mentally retarded are "non-productive individuals." There are people who still fight in the courts against the establishment of community residences in their community. There are still people who do not want to see the mentally retarded receiving an education side by side with "normal children." These attitudes are due to lack of information. I sincerely believe more "Baby Does" will only demonstrate the need for us to take more responsibility in community education.

Community education is not only the responsibility of the professional staff of the Association. It is the responsibility of each and every member of the Association. As parents, professionals

and people interested in the welfare of the disabled, we must spend time speaking about these programs, telling our friends and neighbors about services and encouraging them to visit and participate as much as possible. We must let people know that there is hope and help for developmentally disabled people.

A philosopher once said, "A society's success is measured by how it cares for its less fortunate." I would like to submit to you that a society's success is measured by its knowledge of what should be done for all its citizens and then setting the wheels in motion to do it.

— Richard Swierat,
Executive Director
WARC Newsletter

Fetal defects detection update

A substantial number of genetic disorders work their damage through the baby's lack of some enzyme or other important substance, or through the abnormal accumulation of something else. Early warning that a fetus faces such a problem might, in the future, be followed by treatment in the womb that could compensate for the dangerous excess or deficiency.

The new method is called chorionic villus biopsy. Unlike amniocentesis, which relies on fetal cells found in samples of amniotic fluid taken with a needle through the abdominal wall, chorionic villus biopsy samples fetal tissue directly through the cervix. It is now being tested at several medical centers in the United States and Europe.

The earlier a genetic problem is found in a fetus, the greater the possibility that it might someday be corrected by some form of treatment in the womb.

For example, phenylketonuria, which carries serious danger of mental retardation, is now treated by a drastically restricted diet from infancy onward. Specialists say it is a logical possibility that starting such a diet early in pregnancy, by having the pregnant woman follow it, might improve the baby's chances for a normal life.

PARENT'S CAUTIONED

From: "Footsteps — A Television Series on Parenting — Home Viewer Guide", developed by the United States Department of Education.

Variety among human beings is not only natural, but desirable. By accepting and prizing the differences between your children, you'll be more comfortable both with your children and yourself. You'll be able to experience less of the anxiety and more of the joy of being a parent.

So remember: DON'T

- push your children
- compare them with others
- DO
- respond to children as individuals
- rejoice in their differences

Talking to the doctor about your child

What to tell and what to ask

(These suggestions are intended for families whose children have chronic disabilities, but they may also be helpful to others.)

Sometimes there are medical situations when you cannot be as fully prepared as you might like. Sometimes there are emergencies or highly emotionally charged situations when you simply do not have the strength to be in control. Many other times, however, you can plan and initiate. The following are some suggestions to help families get the most out of interactions with medical professionals. Some approaches require time or money or effort; others do not. We hope you will use what seems helpful to you.

— Betsy Anderson
Federation for Children
With Special Needs.
Parent Professional
Communication Group

GETTING INFORMATION: Identify your concerns — Are you worried about any specific things? Is there something that you or your child simply need to understand better?

Between visits make a list of questions that occur; sometimes they're hard to remember later.

Also make a list of any questions your child may have. (This is one good way to reinforce your child's role in his/her care.)

ASKING QUESTIONS, GETTING INFORMATION: Do ask doctors, nurses and others questions about any aspect of your child's care.

If you wish to ask particularly sensitive questions and your child or other people are present, ask to speak in private.

Keeping in mind your right to ask questions (both as the person who gives informed consent to certain procedures, the one legally responsible for your child, and as the person who pays the bills) be reasonable in the timing. If you have many complex questions, you may wish to arrange a separate appointment when there will be time to discuss them in detail.

Take every opportunity to hear any of the people who care for your child speak to groups. This is an excellent way to hear their broad views. It is also likely to be a setting where you do not have to keep the conversational ball rolling. And you may have a chance to ask questions or hear those asked by others.

Talk to other parents, those with a child with the same disability or with other disabilities. (In most cases other parents are glad to share information and ideas. Time pressure is not usually such a problem, and one need generally not worry about asking "dumb questions".)



Joseph T. Weingold and Jonathan Weingold, two "old convention hands" decide an issue between workshops at Lake Placid, N.Y.

SUMMERTIME FOR LEARNING

A U.S. Appeals Court has held that the three-month Summer break leads to educational regression in handicapped students.

Limits on the number of days a year that handicapped children can receive free public education are unconstitutional, the Court decided in the case of a Georgia policy of refusing to allow Special Education programs for.

This does not fulfill the State's obligation to provide an appropriate education, say the Court.

Medical aspects cited

Women who weighed less than five pounds at birth are more likely than others to have babies needing neonatal intensive care, according to researchers at the University of Washington at Seattle.

"This suggests that factors interfering with intrauterine growth have an impact on the next generation of babies," the researchers said in a study of 748 pregnant women published Thursday in the *Journal of the American Medical Association*.

Maternal birth weight was significantly related, they said, to body size, pre-pregnancy weight, weight gain during pregnancy, baby's birth weight, period of gestation, relative growth in the uterus and the baby's need for neonatal intensive care.

Reduced birth weight may interfere with the growth and development of one or more organ systems, including the reproductive and endocrine systems.

"Possibly no matter how effective prenatal, perinatal and neonatal care become, such care alone may not prevent some problems of pregnancy outcome and underscores the urgency for increased concern for the improvement of maternal and child health," the researchers said.

PARENTS AGE — DOWN'S SYNDROME

Dr. Frank Macinnis, respected medical authority, recently wrote on Down's Syndrome factors. "While it is true that there is a higher incidence of Down's Syndrome in middle-aged mothers, an equally important factor is the age of the father."

In a study recently published in the *American Journal of Epidemiology*, this very important discovery was made: While the Down's Syndrome incidence of a 41-year-old mother and a 31-year-old father was one in 105 births, a 56-year-old father increased the incidence to one in 82 births (Down's Syndrome is a congenital (birth) condition associated with some degree of mental retardation.)

AAMD 30th conference

Prevention, Treatment, and Training: Focus on the Developmental and Behavioral Approaches, was the theme of the 30th Annual Conference of the American Association on Mental Deficiency (AAMD).

The New York State Association for Retarded Children (NYSARC) was well represented during this event. Joan Edwards, chairperson of the NYSARC Prevention Committee was a speaker during a panel discussion entitled "Primary Prevention of Mental Retardation". Other panelists included Dr. Harvey Levy, Department of Neurology, Harvard Medical School, Dr. Robert Guthrie, Department of Pediatrics, State University of New York at Buffalo, and Dr. Robert MacCreedy, Jaffery, New Hampshire, who also acted as session chair.

Mrs. Edwards presented a workshop entitled "Prevention Programs to Lessen the Incidence of MR-DD". Dr. Krystyna Wisniewski, Institute for Basic Research on Mental Retardation and Catherine Farah, Ontario Association for Mental Retardation, Toronto, Ontario, Canada, presented various on-going activities relating to prevention education programs. Examples of topics included fetal alcohol syndrome and educational materials for Junior and Senior high school students.



Aileen Vincent-Barwood, international journalist, tells public information listeners "It is important to cooperate — even when you don't want to."

Tell the truth

BUT AS LITTLE AS POSSIBLE WHEN THE TRUTH DISCREDITS

What to do when the news is bad or a Chapter's bad luck incident is featured in the headlines was the topic of the Public Information Workshop presented at the Convention in Lake Placid. Aileen Vincent-Barwood, former Middle East Correspondent for Canadian Broadcasting System, former Editor of the St. Lawrence Plaindealer, and current roving staff of ARAMCO World, an international publication, told members that "Crises are inevitable. But it will be easier to deal with them if you have established good relations with local media personnel, taken them important well written stories over the past years and established a Chapter policy which designates the best person to speak for your Chapter when the bad times are highlighted."

Kate Klein, Chairperson of the Public Information Committee also acted as presenter in a dialogue with Ms. Vincent-Barwood which brought out the Association's dilemmas, predicaments and fears when a "hot potato" situation occurs.

Ms. Vincent-Barwood stressed that the media considers themselves the "watchdog" of society. Reporters feel they have a responsibility to the public. But reporters must meet deadlines and often don't have time to do lengthy exploration of an event or the considerations which lead up to it.

Not "Out to Get You"

It is important to remember that reporters have an important job to do. They are under orders to get the story regardless of circumstances. So, if the Chapter spokesperson is not available, the reporter must go elsewhere — to other sources — some of whom may be misinformed.

It is important to cooperate — even when you don't want to.

Understanding what "off the record" means is important when talking to a reporter. There isn't the opportunity to go off the record on radio or television (which is spontaneous) but in newspaper reporting you can "establish a contract" about when the information you are giving is on or off the record. Telling what events lead up to an incident is suitable material for "off the record" comments. But, it must be very clear in your mind and the reporter's mind exactly when you are speaking "off the record" and when you have decided to go back on again.

Not-for-profit agencies often do feel that the press is unfair. Aspects of a story are blown out of proportion to feature the drama in an incident, but this can be handled by appropriate cooperation with reporters. Many times this kind of mutual respect can turn what might have been a

derogatory story into one beneficial to the agency.

Build mutual trust by being pleasant. Curt or rude answers make enemies. Respect the media as professionals doing a job and accept their right to probe but when answering them, be brief, direct and positive. Don't waiver, she advised. Don't hedge, but don't blab on either. Tell as much favorable truth as you can when the news is bad, she advised, referring to incidents which may be queried by the press (such as suspicion of rape, hanky-panky with funds) and never plead or threaten or ask to have a story killed.

Ms. Klein cautioned against playing favorites with media. Each newspaper or radio station or television station has its deadlines. The times differ. Try to be fair in giving out your information that one does not, by your actions, scoop the other because of varying deadlines.

In deciding what truth to tell or how much, Ms. Klein cautioned members that the spokesperson must be realistic about what is already known in the community about an unfavorable event. People involved in the affairs may be well known, the event could set off a chain reaction in a community which is thoroughly discussed before any media coverage.

Keep in mind that the smaller the community, the larger the chances that much of the story will be passed around conversationally regardless of press revelations.

It is crucial that one event does not become the image which signifies your association in the public's mind. So, continuous communication with the media about positive aspects of your Association, in the good times, prepares a good relationship for dealing with the bad times.

Console yourself also, Ms. Vincent-Barwood explained, that your story may be pushed aside or fall into a "hole in the news" when other shaking events are occurring at the same time. Bad news doesn't last. Also, remember there is nothing deadlier than yesterday's newspaper.

As a final comment, both presenters urged people in the Chapters to look at each upsetting event as a challenge and opportunity to stress some positive aspects of your ARC's ongoing efforts.

DO YOU KNOW SOMEONE WHO IS NOT RECEIVING OUR CHILDREN'S VOICE?

Please tell that person to send a postal card with name and address to:
Computer Membership Listings
St. Lawrence Chapter ARC
Hermon, New York 13652

Community residences historical perspectives

"One of the most precious and beautiful programs

NYSARC operates" — Marc H. Brandt, Executive Director NYSARC

In order to understand all the changes in community residences, we must see how they fit into what we are now calling the continuum of services, Marc Brandt, NYSARC's Executive Director told members of St. Lawrence Chapter on a recent visit. In 1949 there were few programs in the community for our mentally retarded.

We did not think in terms like "continuum of services" and "least restrictive environment." In 1949 parents who founded the ARC had no alternative to keeping the child at home except institutionalization in a state facility or a private "school". Some counties had trainable classes but they were rare and children in them did not receive the kind of services that any child is entitled to.

So the first program of importance to parents was the school program. After that start, Brandt said, through the collective efforts of all the parents and friends of ARC we became very vocal in Albany. Chapters were formed all over the state. This vocal effort caused bills to be signed into law (for instance, the old Greenberg Bill 4407) which strengthened the right of the handicapped child to be educated in New York State. It is a kind of shame that a law had to be passed to say that children who were born with mental retardation have the same rights as any child, but that's what it took to expand the continuum of services.

SCHOOL TO WORK

The next phase of child development from the experience of our parents in the Association was logically the Sheltered Workshops. Again, there were few before 1950, some voluntaries for a mixed population, but very few for the mentally retarded. The only work specifically for the mentally retarded was organized in state schools or state hospitals. NYSARC then began to exert pressure at the federal and state levels to bring into existence work programs in New York State from the Office of Vocational Rehabilitation. Accompanying Vocational Rehabilitation, was a new concern for prevention of Mental Retardation and also early intervention. It activated pre-school and infant stimulation programs which became more sophisticated in the 1960's and expanded to statewide services because of pressures exerted by parents and friends of ARC.

AFTER WORK — WHAT CARE?

Such growth lead to the important questions parents began to ask themselves and the Association. "Now that we have started these kinds of programs, what will happen to my child when I am not here? What will happen to all the work of our local Chapters and all the good work of our Association — all our hopes and dreams for a good life for our children?"

Parents began to say "I want some assurance my child will always be taken care of!" A need for Community Residences was established. These provide the place forever for a mentally retarded child. It became a very pressing need as seen by our Association because the founder's children were beginning to be adults and growing towards elderly.

In 1957, Mr. Joseph T. Weingold was instrumental in moving the Association to persuade Governor Nelson Rockefeller to pass the Community Residence Act which established by law the creation of Hostels. The very first one in New York State was operated by the New York City Chapter.

In the 1950's and 1960's some 66,000 employees were responsible for not only the developmental centers, but also the psychiatric centers in the state in addition to the alcoholism and drug abuse programs. The Department of Mental Hygiene was medically oriented and controlled with emphasis on the medical problems. The needs of mentally retarded persons, for developmental education programs was not understood.

Although the laws were on the books, there was little to move the Department of Mental Hygiene towards our needs. No guidelines had been established for our kinds of programs funded by Mental Hygiene. So from 1957 until 1972, there were only three new community residences for the mentally retarded opened under the system. Then came the tragic and embarrassing exposure of the Willowbrook and Staten Island Developmental Centers lack of quality of care. With the legal decisions that followed this exposure, a mandate to move out into the community began under the auspices of the new Office of Mental Retardation and Developmental Disabilities.

Now there are 1500 community residences in New York State with plans for more each month. Your Chapter has six, is looking at two more, each representing another facet of the "continuum of services". A Children's Residence answers a need as does apartment style living in a designed residence operated by your Chapter. There are residences for various levels of ability. They range in aspect from Nursing type Homes to Independent Living. They service people leaving the developmental centers and people left orphaned by the death of parents or by the incapacities of the elderly to care for the mentally retarded at home.

We constantly judge and analyze our own efforts because each new program originates its own quality of care aspects which must be scrutinized for alternatives and options towards growth.

We are a unique Association. Our growth, accompanied by conscientious quality assurance directives, keeps us caring, Brandt concluded.



Richard Laurin (far right), executive director St. Lawrence ARC, listens while Marc Brandt analyzes NYSARC's Community Residential growth.

Public Information Committee

Sabbath Sunday—a year around project

ACCESSIBILITY: BEYOND ARCHITECTURE TO ATTITUDES

Historically, full participation by persons with disabilities in congregational and community life was often difficult if not impossible. Not because of their lack of ability or desire to participate, but rather because of the barriers of architecture and attitude.

During the past decade, however, hundreds of congregations throughout New York State have become more accessible to persons with disabilities. Many have found architectural barriers as the first and easiest to overcome while others have developed special programs and ministries for persons with disabilities.

Today, our growth together as God's people has taken us beyond ramps, elevators and special programs for "those" handicapped people, to the realization that God's people includes all of us. We now recognize the gifts and limits of all people. Can we think of persons with disabilities as persons with untapped assets that are needed for the whole of God's people? Can we also take the lead in dealing with the emotional and spiritual barriers that too often hinder true participation and belonging?

Some of those barriers are fear, ignorance, stereotypes, embarrassment, assumptions and stigmas. They all can be overcome with awareness, understanding, action and love . . . all based on the commitment to the dignity and humanity of each person. We each have strengths and weaknesses, needs to give and receive, to love and be loved, to belong and to be included.

Disabilities are far more common than you might think. In fact, at least one person out of ten is affected by some kind of disabling condition. These may include physical impairments, chronic illnesses such as muscular dystrophy and multiple sclerosis, developmental disabilities including mental retardation, epilepsy, autism, cerebral palsy and other neurological impairments and sensory disabilities, such as visual and hearing impairments. If you didn't think you had persons with disabilities in your congregation, think again, and consider those in your community or congregation who may be hindered by architectural or attitudinal barriers from feeling truly welcome, included and accepted.

Access Sabbath - Sunday is one way of helping your congregation to become more aware of and accessible to the needs and gifts of persons with disabilities.

NYSARC
Public Information Committee

Summation by one member of Board of Governors

Amid all the organization machinery that any convention must spin through in its annual renewal of leadership, etc., the major achievements of each convention of an organization with such awesome responsibilities as NYSARC, should, in my belief, be twofold, as follows:

First, to update policies, to reflect changing circumstances and needs, so that we can cope adequately with the new challenges thrust upon us.

Second, to bring to the leading people assembled from all our Chapters the evidence of what is succeeding to help our population, and what is not. Such information can be drawn upon from many sources, not the least of which should be those of our 64 Chapters with some new program to report on. The goal of this aspect of the Convention might be described as "sending the delegates home with their heads spinning," with new ideas, impatient to inject fresh life into their Chapter's programs.

— Convention Planning Committee

"TEN COMMANDMENTS" FOR OUR RELATIONSHIPS WITH PERSONS WITH HANDICAPS

- I. I am God, your Creator; I have brought you out of bondage. Liberation is a sign of the life I give you.
- II. Remember the Sabbath Day, to keep it holy; you shall be wholly before Me — the entire congregation, excluding no one because of disability or handicap. I am God, to whom ALL shall have access; you may place no barriers before Me.
- III. I name you My children; therefore, let no one else define My sons and daughters. Call no one "crippled" or "disabled." They are persons. Persons WITH disabilities — individuals WITH handicaps.
- IV. Fear not one another; I know the confusion of your embarrassment — your fears — your anxieties. Your brothers' handicap — your sister's disability confronts you; you, too, are vulnerable. You are both in My care. You are one in My sight.
- V. Know that I your God placed good in all of you; you shall not look down upon or patronize the person with a handicap. Recognize that the vast areas of personhood shared in common are far greater than the few differences that disability creates between those you call handicapped and the rest of you.
- VI. Your cup runs over with the fullness of life I give you. In your human way you define that abundant life to include education, employment, a place to live, transportation, meaningful activity, cultural expression and civic responsibility. From these opportunities you may not exclude those you call disabled. Your rights are their rights.
- VII. I place within you varied gifts, abilities, strengths. Do not forget these same abilities, insights and knowledge are in those you call handicapped, crying out for expression.
- VIII. Be grateful for the inspiring quality of life within persons with handicaps, which in turn engender within all of you perseverance, humor, coping abilities, patience and creative victory.
- IX. Recognize that in the commonality you all share, there is also frustration, anger, anxiety and despair, reminding you all of your common frailty and your common need for salvation; and calling you to mission, to provide succor and justice for all.
- X. Give ear to My eternal promise, set forth in Scripture, that underneath are the everlasting arms; hold fast to My assurance to all humankind, that goodness and mercy shall follow you all the days of your life, and you will dwell in My house forever.

Amen.

Dr. Richard H. Mattson:

A true seizure is rarely aggressive

Could a person in the middle of a seizure pull out a gun and shoot someone? Is organized, aggressive, directed behavior possible during periods of altered consciousness?

Two years ago an international panel of epileptologists met to discuss these and related questions.

They studied videotaped seizures of 13 patients who were believed to have shown aggressive behavior during their seizures. The patients had generalized tonic-clonic (grand mal) seizures or complex partial (psychomotor) seizures, or both.

"The long and short of it was that we never could document any kind of goal-directed sustained activity of a complex character," panel member Dr. Richard H. Mattson told the American Academy of Psychiatry and the Law.

A true seizure is rarely aggressive, said Dr. Mattson, Chief of Neurology at the West Haven, Conn. Veterans Administration Medical Center. If aggression is present, it is so disorganized, repetitive and stereotyped that it is unlikely to be associated with well-directed, premeditated criminal behavior, he said.

Dr. Mattson's remarks at the meeting were reported by the International Medical News Service.

Although some researchers believe there may be a casual relationship between temporal lobe epilepsy and violence, such a relationship is rare, he said.

In contrast to the thrashing and tonic-clonic muscle contractions of a grand mal convulsive seizure, the typical complex partial seizure "doesn't look like what most lay people think of as a seizure," Dr. Mattson told the assembled specialists.

His audience had to watch a videotape

closely to observe one patient's complex partial seizure, which was captured on a simultaneous electroencephalogram.

The seizure, arising from the right temporal lobe, was described by Dr. Mattson as "absolutely typical."

The swallowing, smacking automatism began suddenly; it was associated with some altered consciousness and amnesia for what occurred and lasted less than two minutes.

"This is generally what they look like," Dr. Mattson told his audience. "This is all there is to it. There are exceptions, but they are unusual."

Another patient displayed the same swallowing, smacking automatism, but she also moved one arm while the other arm lay still. Such purposeless, non-directed movements are also characteristic of this type of seizure, he said.

When the international panel studied videotaped seizures two years ago, some aggressive, hostile activity was observed, but most of the time it was confused and defensive, occurring only when the person was threatened or someone attempted to restrain him, Dr. Mattson reported.

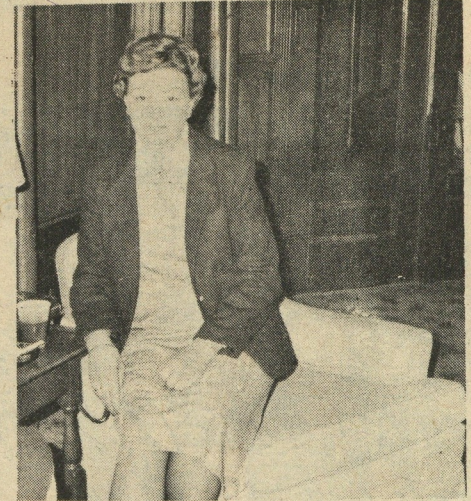
A few instances of aggressive behavior were observed when there was no attempt to restrain the patient.

The videotape of one patient having a complex partial seizure showed her attempting to scratch the person standing next to her bed. Yet when that person moved away, the scratching movement persisted.

Another person was swearing and spitting during the seizure. "I show you these as two best examples of ictal aggression," Dr. Mattson said. "These patients are much too confused to carry out any organized legal activity."

— National Spokesman

Congratulations from all of us at NYSARC!



And then there are the sad times — like saying farewell to past NYSARC Secretary, Shirley Reynolds, who has taken a challenging opportunity to serve the disabled as an executive with the Office of Developmental Disabilities.

Vocational Dates set for rehabilitations goals conferences

Dates have been set for six conferences on Vocational Rehabilitation Goals to be held throughout the State. The conferences were authorized by Commissioner of Education Gordon M. Ambach and the Board of Regents and they will focus on a draft discussion paper entitled "New York State Board of Regents Project on Long Range Goals and Policy Directions for the Office of Vocational Rehabilitation." The Regents Project is being carried out in cooperation with the Commissioner's Advisory Council for Vocational Rehabilitation in order to formally identify and document the direction of planning and policy for services to disabled individuals served by the Department's vocational rehabilitation program. The draft paper includes a project rationale, a mission statement, a section on major issues affecting vocational rehabilitation of disabled persons, and a final section on future goals and policy directions. After the conference series is completed, the paper will be revised to reflect participant comments and suggestions.

The conferences are scheduled to be held in Buffalo on January 12, 1984; in Utica on January 24, 1984; Binghamton on January 26, 1984; in Smithtown on February 2, 1984; in New York City on February 3, 1984; and in Albany on February 10, 1984.

Copies of the draft paper and registration information will be sent to interested individuals who may wish to attend. Contact Jim Tully, One Commerce Plaza, Room 1912, Albany, N.Y. 12234, (518) 473-4822.

Tax deductions for volunteers

A number of tax benefits are available for volunteers under the general charitable contribution deduction of the Internal Revenue Code. The Internal Revenue Service explains this by noting that volunteers can deduct unreimbursed expenditures made incident to rendition of services to a qualifying organization such as Easter Seals. Translated, that means that a volunteer may deduct out-of-pocket expenses incurred while doing volunteer work for certain groups approved by the Internal Revenue Service.

A complete description of Federal tax deductions for volunteers can be obtained from your local IRS office.

Source: VOLUNTEER The National Center for Citizen Involvement.

CHAPTER NEWS

... What our

Albany Chapter ARC



GETTING STARTED — Breaking ground for a new eight bedroom community residence Albany Chapter ARC personnel and friend prepare to dig in! From left, Edward J. Lukomski, Executive Director of Albany Chapter ARC; Mary Caniano, Chapter President; Albany Mayor Thomas M. Whalen III, Cathy Gilboe and Steven Waite.

According to the **Broome-Tioga Beacon** (Editor Brenda Hawley) this ARC selects a theme for its Annual Banquet. This year it was "A Community That Cares."

How busy are Chapters?

HERE IS THE NOVEMBER CALENDAR FROM BROOME-TIOGA ARC

- November 1 BOARD MEETING — 8 p.m.
ARC Facility
Front Street, Binghamton, NY
SYSTEMATIC TRAINING FOR EFFECTIVE PARENTING MEETING — 7:30 p.m.
BOCES Area Center
Upper Glenwood Road, Binghamton, NY
- November 5 BOWLING — 10:00 a.m.
Reno's
143 Baldwin Street, Johnson City, NY
- November 8 SYSTEMATIC TRAINING FOR EFFECTIVE PARENTING MEETING — 7:30 p.m.
BOCES Area Center
Upper Glenwood Road, Binghamton, NY
GENERAL MEMBERSHIP MEETING — 8:00 p.m.
ARC Facility
Front Street, Binghamton, NY
- November 11 WORKSHOP CLOSED IN OBSERVANCE OF VETERANS DAY
- November 15 EFFECTIVE ADVOCACY FOR EDUCATION OF THE HANDICAPPED MEETING — 7:00 p.m.
NYSEG Service Center
4425 Old Vestal Road, Vestal, NY
SYSTEMATIC TRAINING FOR EFFECTIVE PARENTING MEETING — 7:30 p.m.
BOCES Area Center
Upper Glenwood Road, Binghamton, NY
- November 18 SQUARE DANCE — 8:00 p.m.
ARC Facility
Front Street, Binghamton, NY
- November 19 BOWLING — 10:00 a.m.
Reno's
143 Baldwin Street, Johnson City, NY
- November 22 ARC PARTY NIGHT — 7:00 p.m.
ARC Facility
Front Street, Binghamton, NY
SYSTEMATIC TRAINING FOR EFFECTIVE PARENTING MEETING — 7:00 p.m.
BOCES Area Center
Upper Glenwood Road, Binghamton, NY
- November 24 & 25 WORKSHOP CLOSED IN OBSERVANCE OF THANKSGIVING WEEKEND

Chautauqua County ARC plans to develop a Special Recreation Program for Handicapped Individuals. The project will design and provide new and expanded recreation services to 350 disabled adults eligible for state vocational rehabilitation services to aid in normalized living. Federal — \$63,600 funding.

Dutchess County Association for Retarded Children has begun to broaden its base of community understanding and awareness by implementing a new public relations program this year.

According to Executive Director, Linda P. Smith, "The DCARC was a virtually unknown organization in the county. The man on the street thought ARC stood for American Red Cross. Although approximately 235 developmentally disabled persons are employed in one of its' two facilities, John Q. Public was totally unaware of Manu-Corp's (our sheltered workshop) existence."

Start up is professional

After employing a public relations consultant, a three pronged approach toward solving DCARC's public relations problems was implemented. The three prongs, according to Smith, are to be implemented simultaneously. They are: (1) Membership motivation and networking of volunteers, (2) fund raising, (3) publicity and promotions. She explained that by utilizing all three facets of the program simultaneously, one really being dependent upon the other, the impact has begun to take affect within the community.

A complete press list was established and release submitted regularly. Appearances have been made on two cable talk shows and several radio shows. This type and other fund raising events were scheduled. Promotional events geared towards making new friends for the association began. A new membership approach was established, expansion and refinement of lists occurred, and refinement of promotional materials to start a corporate giving campaign commenced. The networking of volunteers started out with the agency's resources and slowly expanded towards utilizing community resources. All phases were initiated within a two month period.

Smith added, "We are in our infancy stages regarding this project. However, people are already starting to notice that we exist and that we have some very fine services and programs to offer the retarded of Dutchess County. The program, although only five months, old, has generated some wonderful feedback from people who never knew we existed. We've started to make a little money, we've improved our promotional materials, such as newsletter, brochure and annual report. During the last five months we've run two fund raisers and one promotional event with another in December. Our newsletter and Manu-Corp brochure have been completely revised and reprinted. An annual report is in the works.

As sharing is our philosophy, we have begun a parent/professional workshop with speakers of interest to folks facing daily problems regarding our retarded population. And in keeping with our philosophy and purpose, projects enhancing community development, are being developed."

We will continue to build a very solid base of public relations operations and hopefully, in years to come, our foundation will be strong enough to support many successful fund raising events which will be implemented and supported by all the new members, volunteers and friends we will have made."



All funds raised from the RUN, WALK, JOG-A-THON helped year, enabling the Association to continue to provide a mo County.

Columbia Chap

The most recent aspect of COARC's service to the mentally retarded and developmentally delayed is its new Infant Stimulation/Pre-School Program, headed by Ghent resident, Mary Baer.

Children between the ages of 2-5 will receive individual attention in socialization and self-help skills, communication and fine or gross motor development.

An added — and somewhat unique — feature of the Pre-School Program is that these 20 children will be working and playing along with some 10 other children of COARC staff and clients in a mainstream setting designed to benefit both groups.

The Infant Stimulation Program, which is already receiving referrals from WIC and Teen Parents, is designed to work within the home, teaching parents such special techniques as holding, feeding and stimulating physical development. Beginning shortly after birth and continuing until the child is 2-3, the new program will offer much-needed emotional, as well as technical support to parents and families. And, when the child is deemed old enough and able to work within the classroom setting, he or she will make the transition from home to pre-school.



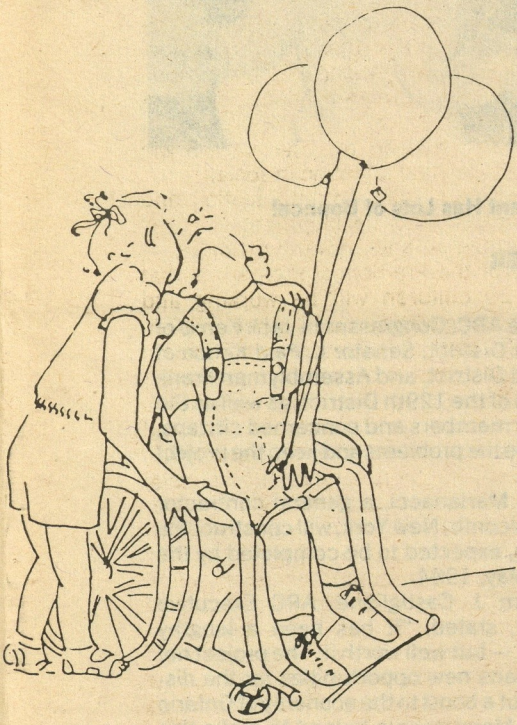
Columbia County Association for Retarded Children held an opening of its early childhood intervention program at Prom provides early detection and intervention for childhood Hudson First Ward Supervisor; Linda Wallace, teacher; La Anderson, COARC Executive Director; Denise Barry, Presid Hogan, Board members.

Our Chapters are doing for our children and adults



ped to offset severe budget cuts imposed upon the Agency last
a most comprehensive program for the retarded in Dutchess

Chapter Pre-School



held an open house Friday, October 28, 1983 following the grand
at Promenade Hill Day Treatment Center in Hudson. The program
hood developmental problems. From left are Jon Grandinetti,
her; Laurie Cordato, teacher; Mary Bear, Program Director; Carol
President of the COARC Board of Directors; Kay Day and Arlene

ERIE CHAPTER ARC

Erie Chapter ARC entertained family and friends at an Open House in the new adult residence, Campus Lane, Amherst, New York.

This spacious ranch house is a barrier free facility which offers multiply-handicapped persons, as well as mobile individuals, an opportunity for group living.

The folks living at the Campus Lane residence are employed in sheltered workshops in Buffalo and Erie County. They travel to and from their work places by public transportation and medicaid carriers.

A second adult group home is located in Hamburg.

The Erie ARC provides residential services to both children and adults in Erie County. The Association operates childrens group homes in East Aurora, Lancaster and Orchard Park.

Each residence accommodates 8 to 10 persons. The homes are staffed 24 hours a day and supervised by a Social Work Counselor.

A first as convention host for conventioners - historic delight!

All the officers of NYSARC, past and newly elected, the ever-increasing Board of Governors, delegates from local Chapters (usually the President and Chapter Board Members and Committee Chairperson, the Executive Directors of our Chapters, and each concerned person who attended the Convention at the Lake Placid Club Resort), thank Mae Heald, Convention Chairperson (and Chapter President), and all the people in Essex Chapter, especially Patricia Antonelli, Administrative Assistant, for making them feel so welcome.

All returned home with renewed purpose in the spirit of the Convention theme — "Joining Together To make It Work."

Essex Chapter reports that the town of Willsboro held a special Board Meeting on Monday, September 26, 1983, to consider a proposal by Charles R. Hayes, Executive Director of Essex County ARC to construct an Intermediate Care Facility in the Town of Willsboro. Mr. Hayes explained that the New York State Office of Mental Retardation and Development Disabilities has requested that Essex County ARC develop three new ICF's in Essex County. Willsboro is one of three towns being considered for these projects.

The proposal passed.

The Towns of Schroon and Keesville have also indicated an interest in developing an ICF. Each facility will cost approximately \$400,000 to construct and have an annual operating budget of \$425,000. Each facility will employ 15 staff members.

FRANKLIN COUNTY ARC

When New York State cut funds to the home for children with disabilities this year, the ARC faced a \$15,000 debt. Rather than close the home, the board of directors has chosen fund raising efforts. Nine children live in the home.

Until recently, there were few residential programs for children in New York because of a lack of funding. Residential services for developmentally disabled children were only available in institutions. Many children who do not need the institutional level of care were placed in facilities such as Sunmount Developmental Center of Tupper Lake because there were no other options, according to Executive Director, Klaus Meisner.

One of the beds in the Moira residence is kept vacant for respite services.



Looking back at last Christmas one of the highlights at the Nassau AHRC Chapter was when a community of Glen Cove fire trucks arrived bearing Santa Claus with high school cheer leaders and members of the local Lions Club. It was all part of the Lions Club annual Holiday Party which is held for the Nassau AHRC children on the Brookville campus.

FULTON CHAPTER NEWS

Fulton County Chapter is very proud of two new programs introduced this fall. The Recreation and Children's Services Departments have developed a new program which includes the participation of adults and children in a "Big Brother/Big Sister" vein. The program has been designed to become a very important part of the Recreation Community Awareness program. The goals are to provide one-to-one attention for the children, to give a sense of responsibility to our adults, to provide opportunities for friendships between adults and children, and to provide experiences that will enhance self-esteem and a better sense of self-worth in our adults.

Activities thus far this fall have included a trip to the Glens Falls Balloon Festival and a Demolition Derby at the Fonda Speedway. Currently we are working on a Thanksgiving Day float for a holiday parade in Johnstown later in November.

The second new program is a jointly sponsored venture between the Fulton County Youth Opportunities Unlimited (Y.O.U.) Program and the Children's Services Department of the Fulton County Chapter, entitled, the "Friendship Program."

The program involves children from our Tuesday After School Recreation Program and several young mothers from Y.O.U., a program designed to serve pregnant women and mothers under the age of 21 and living in Fulton County.

The goals of the joint venture are to provide exposure of children with special needs to young mothers of high risk children, provide one-to-one attention for the children, give a sense of responsibility to parents, provide opportunity for children to broaden their experiences and friendships, enhance community exposure, provide "extra" recreational opportunities to both children and parents, and enhance the

self-esteem in our children and the young parents.

Taking her show on the road is what Fulton County Chapter's Education Coordinator, Kathy Mikulak, does when she visits area elementary and high schools and presents a student participation program designed to develop an awareness on the students' part of what it is like to be disabled. The students are encouraged to perform routine activities as though they are disabled. These simulated disabilities are made possible through the use of wheelchairs, blindfolds, oversized mittens, earplugs, etc.

The program has been in existence for four years and is very well received by the schools. To date, over 100 presentations have been made to approximately 2,100 students.

HERKIMER CHAPTER NEWS

Herkimer County ARC reports that Illion Public Library is currently hosting an exhibit of works by developmentally disabled members of the Herkimer County Community. ARC Counselor Odessa Helmer, said most of the work has been done in the people's homes, and the exhibit is a chance to share this part of their lives with their Herkimer area neighbors. The crafts will be on display through the end of September.

The exhibit is an opportunity to share the interests and talents of these people with the community at large. The room contains examples of latchhook rugs and hangings, embroidery, quilting, as well as sketches. Most of the work represents leisure-time and hobby activities.

All of the exhibitors attend day programs run by the Herkimer County Association for Retarded Children of the State of New York. Those activities, however, are work related.

CHAPTER NEWS Continued....



Harvey Bancroft, president of the Madison Community Residential Project, Inc., breaks ground for a home for mentally/physically disabled adults to be constructed on North Willow Street. Looking on are, from left, Madison County Association for Retarded Citizens, President Lois Jones; Tony DiVeronica Brothers, Inc., the firm that will construct the building; and ARC Executive Director Ray Lewandowski.

MADISON

Madison Chapter ARC received \$5,000 from Rupert Smith ARC board members to purchase a site for a barrier-free community home for adults who are mentally retarded.

ARC Director Raymond Lewandowski said Smith's daughter, now 33 and a resident of the ARC Community home suffers from

cerebral palsy. The home will be one of six in New York State with access for disabled adults. It will not be limited to the elderly but be built specifically for people with mobility problems.

It is expected the home care be a reality by Spring.

CHAPTER NEWS — MONTGOMERY

Montgomery County Association for Retarded Children recently presented their Good Neighbor Award to neighbors throughout the county in recognition of their thoughtfulness and willingness to make handicapped neighbors welcome in the community. These neighbors have offered their help and friendship to the handicapped and have made meaningful contributions in helping the disabled enjoy the benefits of community living.

Rich Minogue, Director of Residential Services for the ARC, presented the awards along with Executive Director, Frank Capone.

Capone has stated that the people of Montgomery County have been outstanding in accepting the handicapped into the community. "Although a few have been recognized with an award the efforts of all are greatly appreciated," Capone stressed.

NIAGARA CHAPTER

Niagara Chapter reports a collection of miniature paintings by former Executive Director, Betty Hilty of Sanborn, NY, was on display at Niagara County Community College in October.

The retired school teacher spent 30 years instructing emotionally disturbed children in Western New York and was active in establishing the first Niagara Falls school for retarded children in 1954. She also served as the first Executive Director of the Niagara County Association for Retarded Children and was listed in "Community Leaders of America" in 1972 and 1976.

ONEONTA CHAPTER

Oneonta Chapter ARC will have a share in restoring the Otsego County Courthouse, largely because they did a good job on the Norwich Courthouse five years ago, county officials said.

Charles Bateman, chairman of the county's buildings committee, said the ARC will refinish courthouse furniture not covered by the general renovation contract.

"The Norwich Courthouse was refurbished five years ago, and they did a good job there," Bateman said of the ARC workers. "Our architect recommended taking a look at them for this project."

He said work to be done by the ARC includes court benches, office furniture and chairs from the grand jury room.

Oneida County ARC held its Annual Volunteer Recognition dinner on November 6th. "This is our way of publicly recognizing the importance of those community minded individuals and organizations who have done an outstanding job of donating their time and energy to the advancement of the ARC."

Angela VanDerhoff

ONONDAGA ARC REPORTS A SPECIAL OLYMPICS BID

A Committee made up of business, government and community representatives has put together a proposal for Syracuse to be the site of the 1987 Special Olympics. The Committee will submit a bid to the Special Olympics, Inc., office in Washington, D.C. and await a decision on site selection.

Orleans Chapter ARC operates

"Rainbow pre-school programs"

A staff of special education teachers, speech therapists, a physical therapist, a parent training instructor and family services coordinator are available to children aged 2½-5 years enrolled in the preschool program, and infants to 2½ years enrolled in the Infant Stimulation Program. Children

in the Infant Stimulation Program receive training through both base center sessions and home visits.

Rainbow Preschool offers educational services free of charge to developmentally disabled children residing in Orleans County. Free transportation is provided.



Orange County AHRC's Education Department Has Lots of Bounce!

ONTARIO COUNTY CHAPTER

Ontario County Chapter has announced plans to begin construction of a ten-unit apartment complex to be located on Pre-emption Road in the Town of Geneva. It will house ten developmentally disabled residents of Ontario County. Funding for the half million dollar structure is coming from the Federal Office of Housing and Urban Development (HUD) and the NYS Office of Mental Retardation and Developmental Disabilities.

Planning began in 1980 when ARC received word that they had been awarded a grant from HUD. Since that time, ARC, HUD and OMR/DD officials have been working closely to see the project become a reality. Several times over the last few years, the project was nearly terminated because of technical and timeline difficulties. Ontario County ARC was assisted by officials from

the State ARC, Congressman Jack Kemp of the 31st District, Senator L. Paul Kehoe of the 53rd District, and Assemblyman Frank Talomie of the 129th District, as well as the Chapter members and concerned citizens, to resolve the problems and keep the project alive.

Frank Marianacci, a general contractor from Holcomb, New York, will construct the building, expected to be completed by the end of May, 1984.

William J. Castiglione, ARC Executive Director, stated, "It has been a lengthy process — but well worth it. The project not only means new opportunities for the disabled, but a boost to the economy of Ontario County. Many people helped to make this project happen. We look forward to their continued support in the future."



Walter Watts Wins Humanitarian Award

For his long-standing work on behalf of the mentally retarded, Mr. Walter Watts receives the very special Humanitarian Award, presented by former Board President, Mrs. Carolyn Smeal, at the Niagara Chapter's Annual Banquet.

CHAPTER NEWS — FULL REPORT

Rensselaer County ARC reports a great deal of success in the public information area as the result of the development of a new slide/tape program. The Rensselaer Chapter has shown this program, which takes 5½ minutes, over 100 times to various community groups. The Chapter is presently working on the development of a series of publications, which will be coordinated with the slide/tape program. Persons interested in learning more about Rensselaer's program are invited to contact Executive Director Jim Flanigan at 518-274-3110.

Riverside Enterprises, the vocational rehabilitation program of the Rensselaer ARC, is benefiting from the development of some new technology in the forestry area. In recent years the National Forest Service has developed a new system, using knit plastic, to keep animals from eating newly planted tree seedlings. Through the Javits-Wagner-O'Day Program, the Rensselaer ARC will be producing over 1,000,000 metal anchors to hold this knit plastic. The Chapter is developing a new off-site, which will employ 12 trainees, to do this work. To obtain equipment for this contract, the Chapter was able to obtain an interest-free loan from a local foundation, with the repayment of the loan based on the profitability of the contract.

ROCKLAND CHAPTER ARC

The Rockland Chapter ARC reports that the residents of the Association for Retarded Children's Viola Road community residence will sponsor a child through the "Save the Children Foundation," according to Residence Manager Pam Gerstheimer.

Each month, John Nicholas Henry of Mineral Bluff, Georgia will be the recipient of a \$16 donation from the Viola Road residents. They also hope to send the child gifts, whenever possible.

Gerstheimer admits the idea was her own. "But the clients saw the ads on television and loved the idea of writing to the family," she explains.

In addition to helping the toddler, Gerstheimer hopes the experience will prove to be educational for the residents. Gerstheimer promises, "They will meet regularly to write letters and maintain a bulletin board with pictures and correspondence from 'Save The Children'."

The money sent to Henry's family will be used for the child's food, education, health care, and participation in community projects. Mineral Bluff is an isolated rural community in the Blue Ridge Mountains.

SCHOHARIE COUNTY ARC

Schoharie Chapter ARC is examining how to better plan for disaster whether natural or chemical, according to Ira Gelinson, Director of Schoharie's ARC. Gelinson, who directs programs for the handicapped of five buildings spread through three towns, said he is now planning to equip all his buildings with transistor radios to keep informed of what's happening on the outside in case other communications fail in a disaster situation.

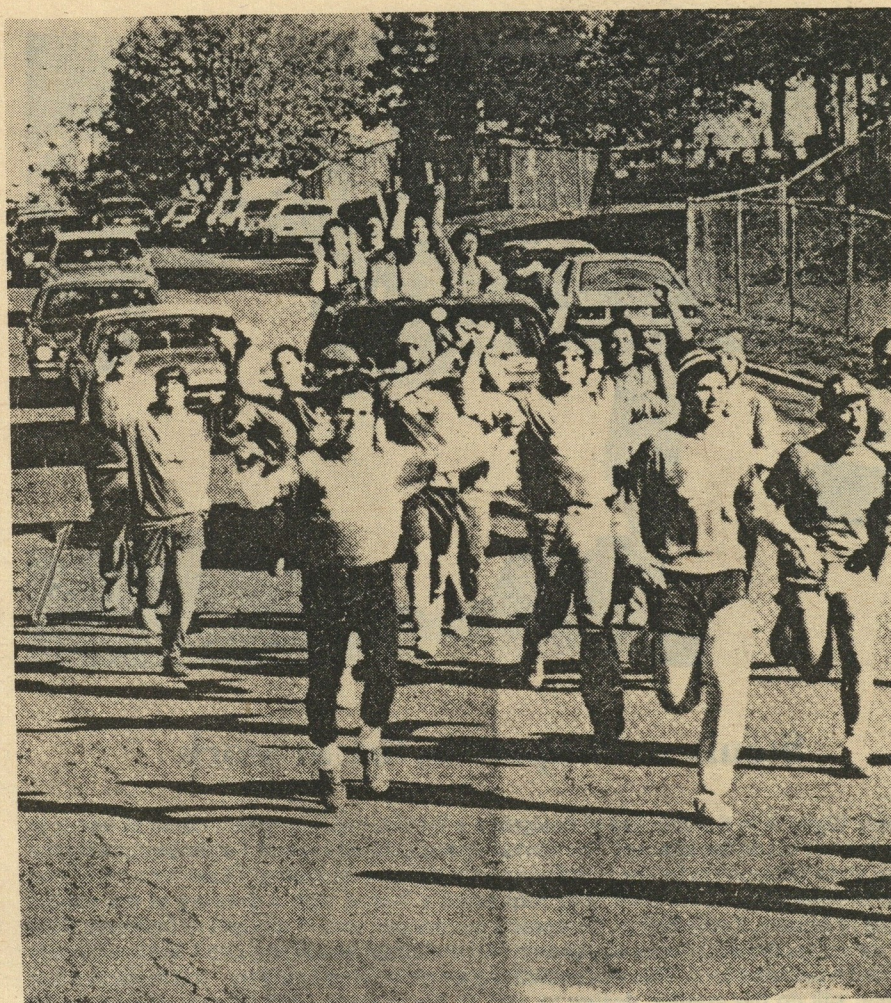
Representatives of several Schoharie County schools and the County Office of Disaster Preparedness (ODP) considered these questions and others in a meeting to develop a coordinated, county-wide disaster plan.

The effort involves planning for tornadoes, hazardous waste spills on highways, storms that destroy power lines and other natural disasters and incidents that could result in serious injury and loss of life.

Ira Gelinson, director of Schoharie's Association for Retarded Children (ARC) which oversees 175 clients daily, said Wednesday's meeting started him thinking in new directions about possible disaster.

"I think it's important because you never know," Gelinson said. "There's a tendency to say 'never here'."

The next step in developing disaster plans will be a meeting with a state legal expert.



Brothers from Sigma Phi Epsilon fraternity, followed by some sisters," shout for joy after arriving in Cornish with an empty keg they had rolled from Syracuse. The activity, in this year, raised \$425 for the county chapter of the Association for Retarded Children, according to Sean Olson, the frat's social chairman, which was more than the \$300 collected last year. He said 25 brothers and four alumni joined the trek, which took six hours.

STEBEN CHAPTER REPORTS

Two people are alive today not only because residential staff is required to have training in CPR and First Aid, but because their care, concern and compassion go beyond the required limits.

One life was saved by Freida Woodhams and Irene Bliss of the Wayland Community Residence. At 1 a.m., May 27, a power failure prompted off-duty Irene to return to the residence to assist Freida during the outage. They relaxed briefly after finding all was well during an initial check of the rooms, then decided to do another check before Irene left. It was then, at 2 a.m., they discovered an unconscious resident who had stopped breathing and had no pulse or heart beat.

With only a flashlight and a candle for light, they performed two-person CPR for seven minutes until his breathing and pulse returned. When the ambulance arrived the attendants administered oxygen, and after being admitted to the hospital his vital signs returned and he regained consciousness. It was determined that he had choked on vomit as a result of a seizure. Had Irene and Freida been content with only what was required of them, the resident would have died before the next check.

The second life was saved by Crickett Butcher, who, at the time, was Community Counselor at Oaklawn Community Residence. The incident is related in her own words: "I would like to share with everyone a rewarding experience I had in a restaurant in Horseheads."

"My daughter and I stopped for lunch. While I was helping myself to the salad bar I heard a woman's voice shout 'Would someone please help me!' Looking up I saw a mother with her choking child. She stood the child on the floor. The waitress came

quickly, raised the child's arm over his head and was hitting him on the back. At the same time the mother had her finger down the child's throat. After just completing a required course in CPR a month ago, I realized more and different help was needed.

"After setting down my salad, I walked over to the mother, knelt down, quietly saying 'I'm trained in CPR, would you take your finger out of his mouth so I can see if he's breathing?' The child was not breathing so I tipped him upside-down over my knee and supported him at his shoulders. I gave him four blows on the back with the pad of my hand near the thumb. My blows were given with an upward thrust. I looked at the child's face keeping him tipped upward, there still was no food, no crying.

"I repeated the upward blows, four in the back area. I looked at his mouth and saw bread, I probed his mouth. Finally the child screamed. After that a large piece of hot dog and roll came up. I wanted to hug the child but he did not like me, he wanted mom. I went back to my seat and ruined a good makeup job with tears. A few minutes later, about ten, I went back to the pregnant mother.

"I explained that her reflexes were normal but could have caused complications. I suggested that the parents take a day and enjoy a course in CPR together. They could get all the information they needed from the American Red Cross.

"Oh yes! The child was fine! He would not eat his dinner but was enjoying ice cream on a stick.

"I won't forget this experience and the feeling of confidence it has given me. One feeling I also carry is... All will benefit from Steuben ARC's Program."

STEBEN CHAPTER ARC

Steuben Chapter ARC reports a special certificate awarded to Freida Woodhams of the Wayland Community Residence, whose quick action and skill helped save the life of a community resident found unconscious in bed in May.

Guest speaker at Steuben ARC Annual Training Day was Joseph Kovler, NYSARC's Associate Executive Director. He said that the major change in the State organization recently has been to develop a more corporate structure. The state agency is seeking to network existing talent and services. He said, "In the future, we may be asking some of your talented people to assist an agency that is having difficulty in a specific area, or offer assistance to your agency from other organizations. We want to bring every Chapter up to the same level of excellence."

Following a brief history of the State operations, he said, "We must keep asking ourselves if the services we are providing are meeting the needs of our clients. It may seem that at times we get caught up with rate settings, cash flow, work flow and so forth. However, if we at the state level do not get involved with these complexities, the local agencies would not be able to provide the programs that are the purpose of our organization."

The Joybells, a handbell ringing group of youngsters from Pennsylvania, are residents of Melmark, a home for the mentally and physically handicapped located in Berwyn, a suburb of Philadelphia.

Over 160 members and friends of the Steuben Association for the Retarded attended a concert by the Joybells at the First Presbyterian - United Methodist Church in Painted Post on October 26, 1983.

Under the direction of Mildred Krentel, co-founder of Melmar, and Music Therapist, Celia Downie, the Joybells performed a concert of handbell ringing selections and vocal solos with hand-signing accompaniment.

More than 60 staff members of the Steuben Association for the Retarded took place in the Annual Agency Training Fest at the Tally-Ho Restaurant in Kanona October 5, 1983. Marilee Hyman, Steuben ARC Executive Director, said "the annual training day is an opportunity for all members of the county-wide agency to get together as a group, meet new people, take part in training activities and discuss mutual problems." She told the group that the agency goals for the past two years have been focused on "climbing out of a hole" of financial instability. With that accomplished, more recent goals have been to solidify the systems and concentrate on agency growth.

SARATOGA COUNTY

Saratoga County Association for Retarded Children Day Treatment Program is contracting with the Wilton Developmental Disabilities Service Office to provide professionally trained home care aides to families with disabled members in their homes. The aides work directly with the disabled family members.

Saratoga ARC reports the Craft and Antique Festival in November, held at the Sheltered Workshop in Balston Spa, was a splendid success. The cooperativeness extended by everyone who attended was the key to its success, according to the Chapter reporter.

The event included flea market tables, crafts, jewelry, Christmas items, antiques and a food concession. Baked goods and hot dogs were contributed by staff, clients, families and friends of the A.R.C. Entertainment was provided by Gorman John Ruggiero formerly "Cappy-Go-Lucky" of TV 23. He was busy playing his guitar and painting faces on children. A guest appearance was made by Chuck-E-Cheese.

Everyone had a great time. We're looking forward to a repeat performance next year!

CHAPTER NEWS — FULL REPORT

NYS Bottle Bill makes for a full day's work

By Deborah Wight

Working inside is like working outside. That's according to one of about 250 participants in the St. Lawrence County Association for Retarded Children (ARC), Judy Foster, who said she sees little difference between her employment at the program's Ogdensburg workshop and work "out there."

With the local ARC for more than two years, she is in its placement program, but believes she needs more time in a few areas before she is ready to enter the community job market.

National Employ the Handicapped Week, Oct. 2-8, brings to public light the productivity of people like Judy.

"Our workers need recognition for their efforts," said Angela Fee, ARC placement specialist who covers the county's three workshops in Ogdensburg, Hermon and Norwood.

ARC director, Richard Laurin, said the primary mission of ARC is to employ the handicapped in a sheltered working environment. "We hope to sensitize the community of our clients' preparation and training for employment outside the ARC," he said.

In conjunction with New York State's September-enforced bottle bill, Ogdensburg's workshop is currently involved in the sorting and separating, boxing and bagging of the returnable containers brought in from surrounding communities throughout the county.

Brought in by the truck load, the bottles and cans come in the State Street ARC building via a new conveyor belt where they meet the hands of workers whose jobs begin there.

Of the three workshop locations, Ogdensburg is the only one to have the bottle bill job site.

"It's quite an operation," Ms. Fee said. "There is a lot involved. After the materials are bagged and boxed, the distributors pick up the finished products."

Work site supervisor Pam Dority said the 30 ARC workers assigned that particular job did 1,500 cases Thursday.

Keeping track of the containers as they pass the workers are electronic counters at the site supervisor's desk, and Ms. Dority said the job includes doing the accounting for the stores as well as the distributors.

Readying program participants for "competitive employment," Ms. Fee said, means teaching them the appropriate skills, including resume writing, interview techniques and filling out applications.

Counselors move from one work area to the next, she said, overseeing the ARC workers at their assigned sites and helping individuals with many problems they may encounter.

Sewing is the third current work project at the Ogdensburg workshop.

Site supervisor Linda Donaldson has only two persons working with her on making drapes for county offices in Canton.

VARIOUS JOBS PERFORMED

About 77 participants in Ogdensburg's ARC programs are placed at various work sites in the local building with some working at more than one job.

Currently, the ARC is contracting with Acco in putting together and packaging binders.

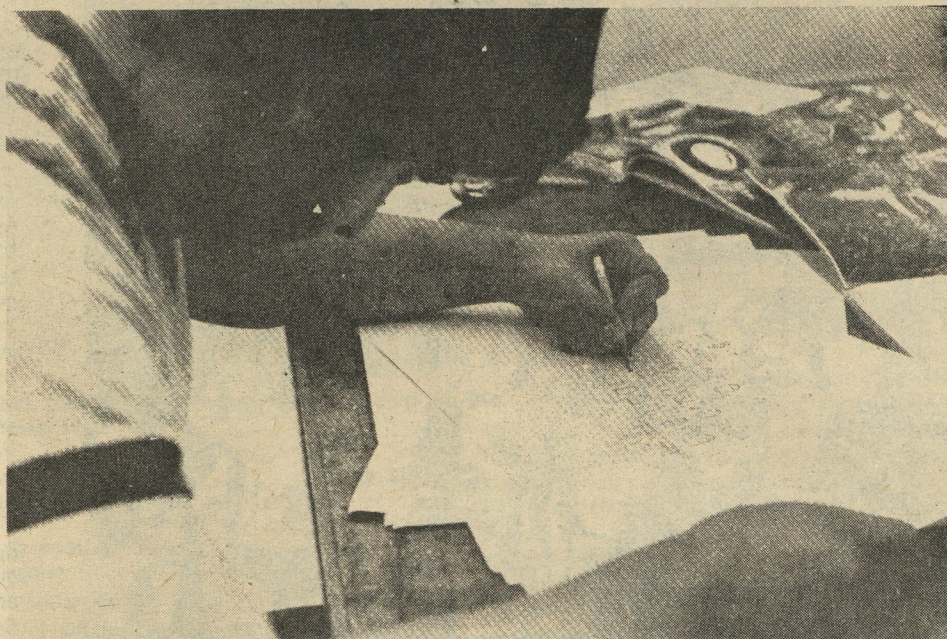
Acco site supervisor, Janice Bice, has about 50 ARC workers employed at her site.

ARC industrial specialist Craig Ballard sets up contracts with outside customers, serving as a coordinator between ARC workers and outside employers. "In developing contracts," he said, "we look at current production standards and norms, prevailing wage rates in the community, etc."

ARC workers earn wages like employers pay employees in the "real world," he said, either at piece rate or hourly pay.

Wages paid are generated through the contracts with the outside businesses, Ballard said.

— Ogdensburg Advance News



Steuben Chapter artist at work

Domenic Giglio is in the process of designing a T-shirt, the first time a client at Services Unlimited has made the attempt. The workshop has printed several T-shirt designs for the Empire State Enterprises for the Handicapped in the past including "I Love New York" and "Made In New York." This time, they requested a T-shirt with a drawing of the capitol building in Albany. Kathy Bailey, Domenic's supervisor, said "I thought of Domenic right away. He enjoys drawing heavy equipment and buildings, and is very good, but there really is not much demand for it. This was something we thought he could try." It is expected that Domenic will do the graphic design as well as the drawing, with several designs to be submitted to ESEH. "We're very hopeful his design will be accepted," Kathy said. "Domenic is excited by the possibility that hundreds of people throughout the state may be wearing a T-shirt of his design."

Sullivan County ARC membership meeting for 185 people was chaired by Ruth Bennett.

The highlight of the event was an award given to Officer Manfred Germann, of the Woodridge Police Department, as SCARC's "Citizen Advocate of the Year." Officer Germann was presented a plaque for his work with several female residents of the ARC's supportive apartments in an effort to heighten their awareness of the community and their vulnerability, and to teach them how to be cautious, security conscious and self-protective in adverse situations. According to Dave Moore, Coordinator of Residential Services for the ARC, Germann "gave of his time in true advocacy for the mentally retarded and developmentally disabled of Sullivan County. Officer Germann has become a friend of the ARC and certainly deserving of this award." Officer Germann spoke of his experiences and appreciation for the opportunity to offer his assistance to those who are perhaps less aware of their place in their communities. Unselfishly, Germann dedicated his award to his fellow officers, giving them praise for their concerns and effort on behalf of all citizens.

Ulster Chapter has obtained a \$441,000 Federal Grant to build an eight-unit, 14-resident apartment complex for mentally retarded adults.

The Department of Housing and Urban Development is distributing the money for the apartments, the site for which has yet to be determined. Unlike a similar UARC apartment project in Saugerties, the new site will be specifically designed for the handicapped, said Peter Pierri, Executive Director of UARC.

Staff will occupy one of the units and provide 24-hour supervision and teaching of skills required for apartment living. The program, however, allows greater independence than a group home, as clients will do their own shopping and cooking and will be responsible for keeping their apartments tidy.

Besides initiating a Respite Network for 24-hour respite (matching families having handicapped members with trained providers who care for the handicapped child or adult in their own homes or the homes of families) has begun a supervised AFTER SCHOOL RECREATION PROGRAM.

Handicapped students engage in swimming, bowling, arts and crafts, cooking, games and sports, movies and trips.

Warren-Washington County's ARC has applied for an eight-bed facility.

A project report submitted by the local ARC Chapter stated that the Association is proposing to purchase an existing structure in Fort Ann and renovate it to accommodate eight ambulatory adult clients.

The facility will strive to create a home-like environment providing the maximum opportunity to learn the skills necessary for independent living. As clients develop skills, moves to a less restrictive environment such as community residences will be encouraged.

However, due to the severity of the clients' conditions, the sponsor anticipates that most placements in the facility will be for five to ten years.

All clients placed in the proposed facility will be provided with day program services at the Community Workshop Day Treatment Program, the work activities program or sheltered workshop.

Community League — Wassaic Center thanks OCV and all the friends from Chapters all over the State who have written or sent cards of encouragement to the recuperating LEO FIXLER and MICHAEL STYLER. 1984 was welcomed in by Hollis Shaw addressing the highlights of 1983 and the goals of 1984. Musical entertainment was provided by several talented residents of Wassaic. The star of the show was Clarence Guthrie. His voice "has thrilled many including David Susskind."

How to help kids fly safely

Until now, very young children have had to be held in their parents' arms during airplane takeoffs and landings or when there was turbulence, since airplane seat belts do not fit infants or toddlers. (This arrangement is no more desirable in an aircraft than in an automobile, for few parents are strong enough to hold on to the child in a true emergency, and even if they succeed in doing so, holding the child the wrong way can still cause serious injury.)

Recently, the Federal Aviation Authority began certifying the use of portable safety seats for children in most types of commercial airliners. Stuart Miller, a commercial pilot and aviation consultant who has been lobbying for such approval for the last 12 years, was instrumental in developing the first such seat approved: an improved version of a car seat made by Cosco/Peterson, a juvenile furniture and safety-equipment manufacturer. In fact, the model 78 Safe-T-Seat can be used in either cars or planes.

Essentially, the safety seat is a molded-plastic bucket seat in a tubular-metal frame. Used in conjunction with the standard seat belt, it can secure a child up to 40 pounds in weight and 40 inches in height—roughly up to four years old. The frame is shaped for a good fit with the airplane seat and adjusts so that it aligns with either the upright seat-back position required for takeoffs and landings or the reclining positions. Miller says FAA-supervised tests have proved this frame strong enough to protect a child from injury if the seat back is flung forward during a rough landing or a sudden stop while taxiing. Another manufacturer, Century Products, makes four car and plane seats that have met FAA approval. They range in price from \$35 to \$65. For information: Cosco/Peterson, 2525 State Street, Columbus, Ind. 47201; Dennis Reddy, Century Products, 1366 Commercial Drive, Stow, Ohio 44224.

— From Technology Illustrated Magazine, October, 1983

Westchester Association for Retarded Citizens

WARC has a plan of how best to use donations to better the lives of the retarded. Agency priorities are set years in advance, with goals constantly being re-evaluated in light of changing factors. But are you, our friends, planning so that you may adequately provide for your own needs while also remembering your charitable giving interests?

Any financial well-being and charitable giving should begin with an "Estate" plan, which starts with the conservation of property and ends with a careful provision for the distribution of this property before or after death. Everyone has an estate of some sort. An estate, after all, is not just real estate; it is also money, stocks, bonds, life insurance, cars, furniture, or jewelry. . . in short, everything you accumulate during your lifetime.

Someone once said: "If I were a rich man, I would plan my estate carefully. If I were not, I would plan my estate more carefully, because the smaller my estate assets are, the more careful I should be with what little property I own." This article is the first in a series designed to help you plan the conservation of your own assets so that you may live better and experience the joys of giving to others, without depriving your own families. Remember that I will be giving you general ideas. In order to incorporate these ideas into your own, personal "estate" plan you will need the professional help of your attorney, insurance agent, accountant, or stock broker.

A time to be single, to marry, to be young to grow old

Learning how to care for children with handicaps

By Ann and John Murphy

The doctor was not smiling. There was a look of sadness and pain on his face. He chose his words carefully; very slowly and patiently he told the young couple: "Your baby girl has Down's Syndrome. . . let's talk about this; I want to help you."

If this had happened 50 years ago, the scene would be entirely different. For, in those days many mothers and fathers did not deal with handicapped children. They never saw them and they never held them in their arms. If a child was born with a serious problem, he or she was frequently given over to the state and one of our large government institutions would care for this child.

Now, however, the trend is to keep one's baby and care for the child at home. Mothers, fathers, brothers, and sisters share the happiness and the burdens of nurturing these handicapped children. It is not easy; it can be truly rough.

Clearly, the number one problem in raising a handicapped child is that of "Stress." Mothers, fathers and siblings:

- Face a daily reminder that the handicapped child is not like others in the family, at school or in the neighborhood.

- Feel the social stigma and are not always fully accepted or respected by other parents.

- Realize a lack of interests in common with other families.

- Worry about the difficult social adjustment for the handicapped child.

- Are deeply concerned about the child's progress in school.

But, in spite of all these hardships, many of today's mothers and fathers courageously and lovingly wrap up these precious little bundles and take them home.

Their handicaps are sometimes known at the time of birth, or other times they are not discovered for many weeks, months or even years. Their disabilities include:

- Blindness or Partially Sighted
- Deaf or Hard of Hearing
- Mentally Retarded
- Speech and Language Impaired
- Physically Handicapped
- Learning Disabled
- Emotionally Disturbed
- Autistic
- Aphasic
- Developmentally Delayed
- Multi-Handicapped
- Cerebral Palsy

Since it is only within recent years that families have become a topic for research and study, it is not surprising that we have more questions than answers in dealing with handicapped children.

There exists throughout our land a desperate, urgent need for much more research, study, support groups, parent education programs and trained professionals to help these exceptional children and their families.

And until this happens, the stress goes on for many families. Sadly, the research journals indicate that:

- There is a increased rate of divorce and suicide among parents of handicapped children.

- Increased family tensions combined with the child's decreased ability to achieve has led to greater risk for child abuse.

- Financial difficulties in families grow larger due to the need for special equipment, special medical care and special programs.

What should a parent do if they are raising a handicapped child? How should he or she feel? What kind of help exists today?

1. YOUR ACCEPTANCE AND YOUR LOVE. Accept your child, love your child and be proud of your child. He may not be the brightest, most handsome kid in the neighborhood, but he is yours and he needs your love.

2. LEARN as much as you can about his handicap. Try to understand it. Read books, magazine and newspaper articles and talk to authorities in the field. The more you know about the problem, the better you can deal with it.

3. SEEK HELP FROM OTHERS. Seek medical, educational, financial, religious and emotional help from other people. Don't be afraid to ask questions, knock on many doors, write letters, make phone calls and ask for help whenever and wherever you can.

4. JOIN A SUPPORT GROUP. You can accomplish very little in life by yourself. But when you go in with others who share your concerns, then you can truly conquer many obstacles. If no support group exists, why not start one?

In conclusion, we would like to state loudly and clearly that there are many families today who are doing a wonderful job in raising handicapped children. They set a shining example for others to follow. In these homes, handicapped children are accepted and loved. And because of this, these boys and girls are growing and learning and achieving their reachable goals.

— North Country Catholic

Brothers and sisters plan link up

The first National Seminar of Siblings of Mentally Retarded and Developmentally Disabled Persons, co-sponsored by AHRC, was held on May 19 and 20 at New York University. More than 200 siblings, parents, and professionals from throughout the United States attended the two-day meeting.

A highlight of the conference was an award to AHRC by Kean College's Mental Retardation Institute and New York University's School of Social Work, co-sponsors of the program. The award read, "This citation is awarded to the clients, parents, siblings, staff, and Board of Directors of the Association for the Help of Retarded Children, New York City Chapter, for their pioneering efforts and social innovation in serving siblings for the past 25 years 1958-1983." President Walter Redfield accepted the award for the Chapter and pledged to continue to build a dynamic "Sibling Network" in New York City and New York State.

SIBLING CONFAB IMPORTANT

Kathryn Edmundson, a sibling panelist, stressed the importance of siblings having opportunities to meet each other and to work out their problems together. She said, "Sibling groups and sibling networks are very important. It's hard to relate to someone you feel can't understand your feelings as a sibling."

The program and workbook of the seminar are available for \$6.00 to cover printing and mailing. If interested, send a check made out to NYC AHRC c/o Lucy Garcia, AHRC, 200 Park Avenue South, New York, NY 10003.

New children's hospital

will offer Dentistry for the Disabled youngster



DRAMATIC CHANGE: New in children's dentistry is orthognathic surgery, in which a team of oral surgeons and orthodontists - headed by Stephen Sachs, D.D.S., Chief of



Oral Surgery - performs correction of orofacial deformities - as shown in these before and-after photos.

— September 1983 Pharmacy Times

Sophisticated treatment for disabled

For over 20 years, the Department of Dentistry at Long Island Jewish - Hillside Medical Center in New Hyde Park, New York, has been a major regional center for the referral of children who need special oral care. These are youngsters with such developmental disabilities as mental retardation, cerebral palsy, seizure disorders, cleft palate, childhood psychosis, and hyperactivity. But, pediatric dentistry at Long Island Jewish (LIJ) will reach new heights when the 5-story Children's Hospital opens in the fall. Then, pediatric dentistry will have a special place for these special disabled youngsters.

"We have geared our new dental facility to provide approximately 15,000 patient visits each year," says Saul Kamen, D.D.S., Chief of Pediatric Dentistry at LIJ. "It will be a mecca for all those children who require specialized dental care and have not been able to receive it." Dr. Kamen speaks with an expertise that comes from many years of serving the dental needs of disabled children.

The Children's Hospital Dental Department will provide services to a wide spectrum of children and young adults, including the relatively - healthy child as well as the severely - disabled youngster.

— Honey Carlton Foster, M.S.

Taking part pays off

Hundreds of dollars were awarded in 1983 to winners in the Scholarship & Awards Competition. Each year the Scholarship & Awards Committee reviews applications and after difficult deliberations selects the recipients. This year's winners of the 1983 Joseph T. Weingold Scholarship were Patricia Lynn Burns of S.U.C. at Geneseo, and Debra Pernick of S.U.C. at Buffalo; the James Reville Scholarship 1983, Carol Ann Bright of SUNY at Geneseo and Eleanor Pattison of Antioch - New England. The Jonathan Weingold Scholarship winner this year is Catherine Small of the Ontario County Chapter.

Several cards and letters have been received in appreciation of the NYSARC Awards and Scholarships. Excerpts from a letter received from the first Jonathan Weingold Scholarship recipient, Marilynne Lipshutz follow:

"It's been an interesting experience to be just a student. Not having to work fulltime is affording me the necessary opportunities to study and research. I'll be sending the Weingolds a progress report soon. The Weingold Award was the fulcrum that got me going. I appreciate it."

Enclosed with Miss Lipshutz's letter was a copy of an article she co-authored entitled, "Nursing Care of the Mentally Retarded: Communication Issues" printed in the *Issues In Mental Health*

Nursing bulletin. It is most gratifying to get that kind of feedback from our scholarship winners.

The Christmas Card Design Contest was held again this year and the entry from Allegheny Chapter's James Devore took first place. Suffolk's Roberta Hanley was awarded second place for her design, and Virgil Hightower of Letchworth Village Developmental Center was third with his entry.

The Employee of the Year Awards were made again in cooperation with OMR-DD. NYSARC's contribution is a \$50.00 check for each of 40 honorees in the OMR-DD, two from each Developmental Center, and having the plaques engraved, while OMR-DD pays for the engraving and the luncheon.

The Employer of the Year Award for 1983 is to be presented during the Convention Dinner to a representative of Niagara Chapter's Ponderosa Steak House.

Each year a few more Chapters set up local Award Committees, and it is suggested that local activity coincide with State Awards.

Kay R. Nogaj, Chairperson

Black and White photos only are acceptable to *Our Children's Voice*. Many lovely color photos have had to be discarded because of the printing process.

— Editors, OCV—

Read up, then speak up

BOOKS

Brown, S. & Moersch, M. (ed.) **Parents on the Team.** Ann Arbor, MI: University of Michigan Press, 1978.

This book, including articles written by both parents and professionals, covers such topics as parent advocacy and families as resources and suggests a variety of models for meaningful partnerships.

Chinn, P. & Winn, J. & Walters, R. **Two-Way Talking with Parents of Special Children.** St. Louis, MO: C.V. Mosby, 1978.

This book develops an extensive model of the communication process, particularly between parents of children with special needs and the professionals who work with them. The process is described in a transactional analysis framework and includes particularly good discussions of effective listening; non-verbal communication and giving and receiving feedback. The chapter on families of special needs children is somewhat stereotyped. Case studies are included.

Howell, Mary. **Helping Ourselves: Families and the Human Network.** Boston: Beacon Press, 1975.

This book examines how families might develop their own strengths and resources to work with such institutions as schools and medical systems.

Klein, Stanley. **Psychological Testing of Children: A Consumer's Guide.** The Exceptional Parent Press, 1977.

This is a guidebook for consumers which briefly examines many of the standard psychological tools used with children, particularly children with disabilities. The book gives parents background information and encouragement to ask what information tests can and cannot provide, and how the information will help in planning for their child.

Seligman, Milton. **Strategies for Helping Parents of Handicapped Children: A Guide for Teachers.** New York: Free Press, 1979.

A very full book on relationships between parents and professionals. It is written particularly for teachers but is certainly interesting and useful for parents and other professionals as well. Chapters on listening skills, barriers to communication, and parent-teacher conferences are particularly interesting. Many learning exercises are also suggested. The background chapter on families of special needs children is somewhat stereotyped.

Guide for college bound handicapped students

Higher education opportunities for disabled people have dramatically increased in recent years. Now, disabled students may be pleasantly surprised to find a broad range of choices regarding colleges they can attend. These students can succeed if necessary services are available; there are no physical barriers to impede them; and if policies and procedures encourage them. **Directory of College Facilities and Services for the Handicapped**, just published by The Oryx Press, can help handicapped students choose the college that best suits their special needs.

Edited by Charles S. McGeough, Barbara Junjohan, and James L. Thomas, the **Directory of College Facilities and Services for the Handicapped** was compiled from questionnaires sent to every institution of higher learning in the United States, its universities. Institutions are listed alphabetically within geographic location. And, a selective list of resources supplies additional aid to professionals working with handicapped postsecondary students.

This guide contains a wealth of valuable information about special facilities and

services, physical terrain, and auxiliary aids at each institution, as well as demographic data, degree or certification granted, and the name and phone number of a contact person.

Directory of College Facilities and Services for the Handicapped will be an invaluable resource for school and rehabilitation counselors, parents of disabled students, and college-bound handicapped people; it will also provide postsecondary institutions with a basis for comparing their own programs to others.

The **Directory of College Facilities and Services for the Handicapped** is available from The Oryx Press, 2214 North Central at Encanto, Phoenix, AZ 85004. The **Directory** (360 pages - Clothbound - ISBN 0-89774-004-1) is priced at \$80.00. There is no charge for postage and handling on prepaid orders.

READING AND WRITING FOR INFORMATION:

Read everything you can find about your child's disability or about disabilities generally. Parent organizations and agencies have compiled information that other parents have found helpful. The material is usually very good. Also ask them about books. Public libraries are beginning to have more material available on this topic. The Federal Government has a free information center for parents — write Closer Look, P.O. Box 1492, Washington, D.C. 20013. However, the best source for written technical medical information is a medical library. Journal articles usually contain the most up-to-date material. Medical libraries are sometimes difficult to get into, but use persuasion or ask medical people you know who work with your child for assistance.

Write to anyone — parent or professional — seeking information, seeking change, or pointing out problems. Read your child's medical records and add written comments to the record if you think they will add information.

Ask those who work with your child if there are professional journals for your child's disability or some aspect of it. Also, ask if they know of any relevant articles that could help you understand your child's problem (or what to do about it) better.

Ask if there is written material available on any of the tests or procedures your child may have. The more you know, the more you will be able to help your child.

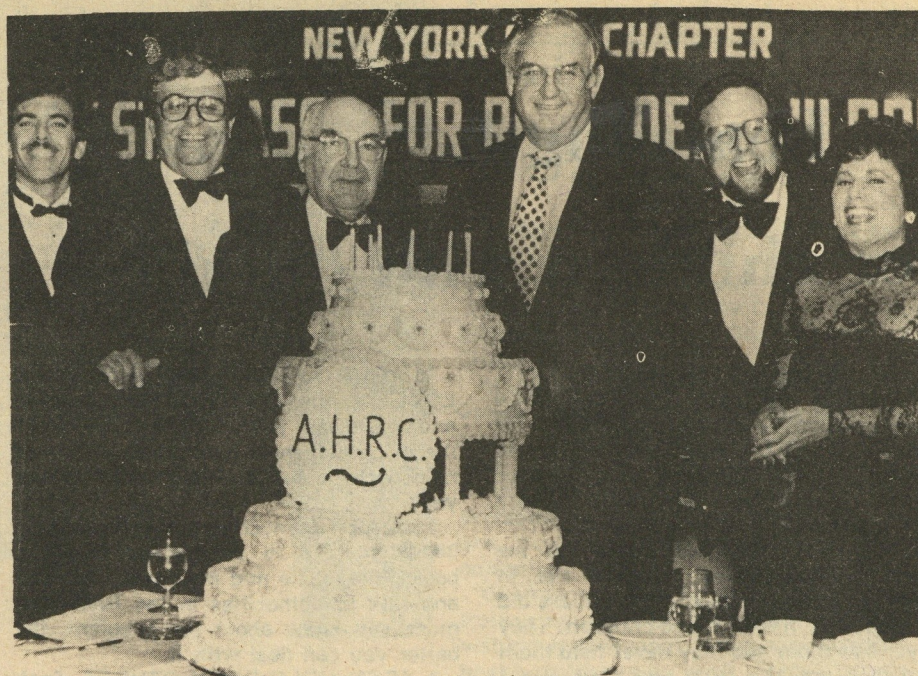
FURTHER SUGGESTIONS AND STRATEGIES: When talking with professionals bring out, and ask them to bring out, any positive progress your child has made (this approach can be psychologically supportive to you and your child — medical situations are often oriented toward problems, and progress and development tend not to be emphasized). If you don't know, ask what the next logical areas for change — progress might be.

Find someone involved with your child's care whom you respect and can talk to — here knowledge as well as personality are important.

Know your rights and your child's rights. If your child is seen by a number of specialists, consider asking all of them to meet together with you to discuss progress, future goals and plans — perhaps once a year (this is obviously much more possible if the specialists are within the same hospital).

If you need a letter of support from one of your doctors (for SSI, or any other reason) be as specific as you can about what information is needed and what points might substantiate your view, claim or request.

Try to anticipate any issues that may arise before you go for your appointment. Once the rush is over, think over your experience and think about what you might have done differently — and write it down. When you can, follow up with those who care for your child. Let them know what things were particularly helpful and



It was all smiles at the 34th Annual Dinner that this year honored Senator Lowell P. Weicker with the Humanitarian Award. Shown on the dinner dais (from left to right) are TV's Arnold Diaz, the master of ceremonies, Irving Gutin, dinner chairperson, Walter Redfield, AHRC President, Sen. Weicker, Michael Goldfarb, AHRC Executive Director, and Irene Platt, former AHRC President and now President, New York State ARC.

appreciated. Also let them know when changes or improvements need to be made. Be as specific as possible and offer any suggestions you have.

ARTICLES:

Barnlund, Dean C. "The Mystification of Meaning: Doctor - Patient Encounters," *The Journal of Medical Education*, Vol. 51, September, 1976.

This article gives a brief, clear analysis of major barriers to effective communication between doctors and their patients. Excellent.

Besch, Linda B. "Informed Consent: A Patient's Right," *Nursing Outlook*, January, 1979, pp. 32-35.

This article analyzes some of the court decisions which have brought about informed consent laws and discusses the difficulties in putting the laws into practice.

Bok, Sissela. "Lies to the Sick and Dying," *Lying, Moral Choice in Public and Private Life*. New York: Vintage Books, 1979, pp. 232-255.

A provocative examination of how and why medical personnel at times withhold information from patients and the effects of this practice on both the patient and the doctor.

Fischbach, Sionelo-Bayog, Neddle and Delbanco. "The Patient and Practitioner as Co-Authors of the Medical Record," *Patient Counseling and Health Education*, First quarter, 1980, pp. 1-5.

This article documents an interesting study at Beth Israel Hospital, Boston, in which patients and their doctors wrote the patients' medical records together. The article documents the treatment and other benefits to both patient and practitioner and also some of the drawbacks.

Korsch, Gozzi, Francis. "Gaps in Doctor - Patient Communication," *Pediatrics*, November, 1968, Vol. 31, No. 5, pp. 855-871.

A report of a study of 800 outpatient visits to a children's hospital exploring the effect of the verbal interaction between doctor and patient on patient satisfaction and follow through.

All of the above may be obtained from: Federation for Children with Special Needs, 312 Stuart St., 2nd Floor, Boston, MA, 02116.

"Baby Doe" panels urged

New York State will ask hospitals to establish guidelines for ending life support for terminally ill or deformed infants, such as "Baby Jane Doe," health commissioner Dr. David Axelrod said.

Axelrod, speaking at a conference on perinatal ethics, in November, said the procedures would be designed to give parent of deformed infants information about the chance for survival.

In the "Baby Jane Doe" case, the unidentified parents decided against allowing surgery. The state's highest court, the Court of Appeals, sided with the parents, but the Reagan administration has tried to intervene in the case.

To avoid such legal problems, hospitals should form review panels to consider each case and discuss it with parents, Axelrod said. Disagreements could be appealed to a state board which Axelrod said will be formed.

LEGALITIES OF CONSENT

An added factor, some experts noted, is that unlike cases involving adults, with babies there is the additional consideration of the rights of the child's parents.

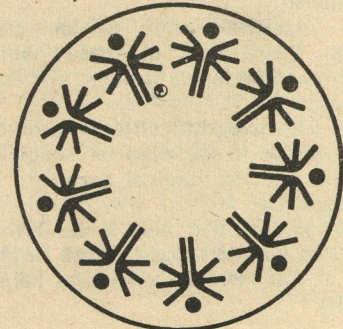
Robert A. Burt, professor of law and medicine at the Yale Law School, said "I like the idea that someone is looking over the decision-making. What I don't like is the Government is always going to say, treat, treat, treat. That is not always the correct ethical response in all matters."

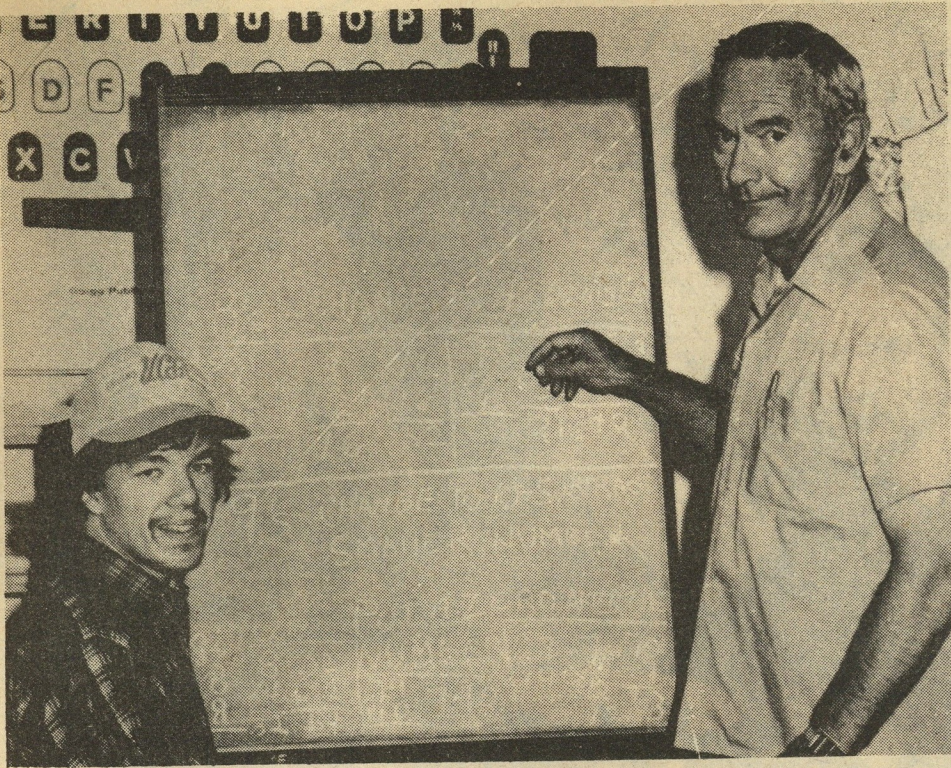
VATICAN PAPER BACKS SURGERY FOR BABY DOE

The Vatican newspaper endorsed attempts to prolong the life of a severely handicapped Long Island baby girl whose parents have chosen to reject corrective surgery.

L'Osservatore Romano, the Vatican newspaper, printed a news account of the case followed by an editorial in November.

SUPPORT SPECIAL OLYMPICS





Irv Campbell and eager student, Kevin Colby.

Photo by: Lenny Hall

Medicaid and SSI waivers for keeping children home

President Reagan focused national attention in November 1981 on three-year-old Katie Beckett of Iowa who continued to be hospitalized despite the fact that her medical conditions could be treated at home at substantially less expense. At home she would have lost Medicaid and Supplemental Security Income because of SSI-deeming rules which were inapplicable as long as the disabled child remained institutionalized. The Secretary of Health and Human Services issued a waiver enabling the child to move home, retain her SSI and Medicaid eligibility, and continue to receive medical treatment at a substantial savings to the Medicaid program.

As a result of situations like these, a Federal Board was established to rule on individual cases, where application of deeming rules would disadvantage individuals and lead to care in more expensive institutional settings rather than in the home or community. The Board is intended as an interim measure until states develop waivers under Section 2176 of the Omnibus Reconciliation Act of 1982 (P.L. 97-35) by which Congress enabled states to offer a wider variety of home and community-based services to individuals who otherwise might need to be institutionalized.

The New York State Department of Social Services issued a release to local districts on the process of referring persons to the Federal Board for waiver of SSI-deeming rules. There are two basic conditions necessary before the Federal Board will consider a request to set aside deeming rules for legal responsibility:

1) Enabling the applicant to be eligible for Medicaid coverage of home-based care will result in lower Medicaid costs for that person; and

2) The quality of home-based care will be as good or better than the alternative of institutional care.

If local social services districts identify or receive referrals of individuals who are currently institutionalized or who are being considered for institutionalization and who meet the two requirements listed above, they have been invited to refer these individuals to the State Department of Social Services. The referrals will then be forwarded to the Federal Board for determination of how much income is to be deemed to the individual. Once deeming rules are set aside for an individual, this will remain in effect until the individual is included in a waiver under Section 2176 of

P.L. 97-35 or until his/her circumstances change.

For further information, contact: Elizabeth Calkins at 1-800-342-3715 extension 3-5535.

— Quality of Care —

Karin Burgess resigns

In September, announcement was made of the resignation of Karin A. Burgess as Executive Director of the Cortland County Chapter of the State Association for Retarded Children.

In a letter to the board of directors, Mrs. Burgess wrote that she was resigning, "in order that I might pursue a career in a different area." She will join Shearson - American Express Inc., in Ithaca.

The resignation took effect October 31. "This decision is not an easy one," she continued, "since working with and for this Chapter, and for the benefit of those who are mentally retarded and developmentally disabled, has been a very large part of my life since the establishment of this organization 17 years ago."

Burgess was appointed acting director of the local ARC in May 1978 and became director later that same year.

A volunteer for many years in the field of mental health and mental retardation, she served nine years as a member of the Cortland County Mental Health Board — four of those years as a member of the executive committee of the State Association of Community Mental Health Boards.

As a six-year member of the board of directors of the Murray Center for the Handicapped, she was involved in the establishment of the Work Activities Center for severely retarded adults.

Currently, she served as chairman of the New York State Council for Mental Hygiene Planning, was president of the Board of Visitors of the Syracuse Developmental Center, and a member of the subcommittee for mental retardation and developmental disabilities of the county Community Service Board and of the Children's Advisory Council of the Department of Social Services. She has been a member of the Occupational Education Advisory Committee for Cortland-Madison BOCES.

She also serves as treasurer of the Community Council and is a member of Zonta Club of Cortland.

Volunteer Profile:

Columbia Chapter ARC Friend - To - Friend

When Irv Campbell suffered a stroke in 1979, he retired from 20 years of service with Prudential. Never one "to sit around and do nothing," he immediately picked up on a suggestion by his friend, Ken Smith, a COARC employee, to come over and do some volunteer work.

The happy result of this suggestion is Campbell's two-day-a-week, six-hour-a-day math program, which he established in March, 1980, and has continued ever since.

"One of the things you find out very quickly is that work has to be on a one-to-one basis," he says. "There's too much distraction with a group. Also, each individual is at a different skill level, which entails different preparations for each session. Their attention span is also important, since the accuracy of work trails off quickly as they tire. We don't want them to lose interest."

Campbell meets with six clients on each of his scheduled days, generally for half-hour sessions. There is a standby list, should a regular student become ill, as well as a waiting list to enter the program. Though his ultimate goal is to prepare a client for the High School Equivalency Certification exam, his individualized teaching also includes reading a calendar, handling

coins and telling time — "Whatever fits the individual client's needs and skill level."

"Repetition is the key," he emphasizes. "There are some very sharp minds in the Workshop, and some who I know there will be no progress with. Retention is another key factor in math, which sometimes creates a tough situation when a client can't remember things from one day to the next."

"You have to constantly evaluate from the client's standpoint," he stresses; "Is it doing any good? If you're going to subject them to a situation where they're not being successful, then you're not accomplishing anything from their standpoint."

Campbell is unabashedly enthusiastic about his 3½-year association with COARC: "They're terrific people," he says; "much more receptive and open to someone who tries to help them."

"Some of these people have had a pretty tough time of it over the years" (his students range in age from 18-60), "and when someone comes along and says 'Let me help you,' you become a real friend. They're not in any way bashful or shy about letting you know it, either, and that's where the rewards come in — the feeling that you've established a valuable communication and friendship."

Network is proposed For organ transplants

A Federal bill that would outlaw the buying and selling of human organs and establish a nationwide transplant network was introduced in the House in October.

"The current scramble for organs has resulted in a variety of ad hoc case-by-case solutions," said Representative Albert Gore Jr., Democrat of Tennessee, author of the bill. "The time has come for solving this problem as well as it can be solved for all those who need transplants. Clearly a national strategy is necessary."

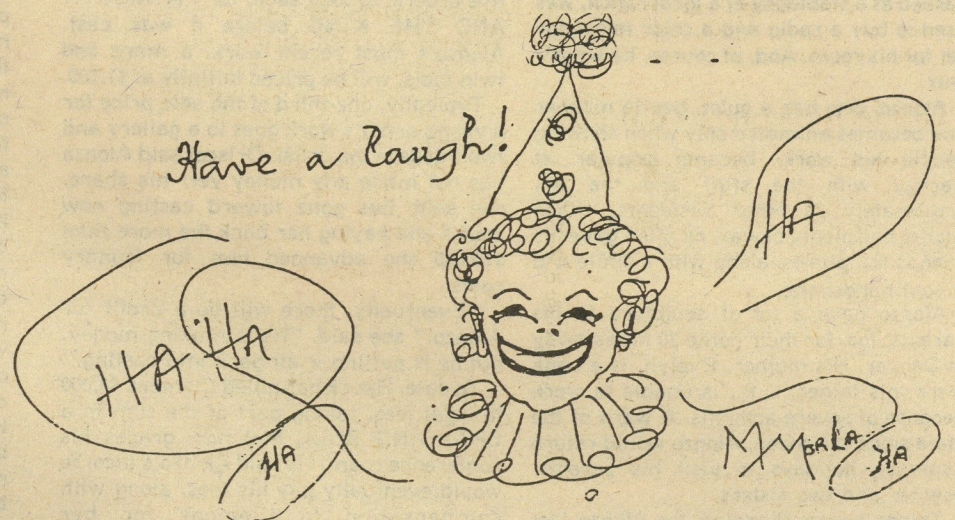
Referring to the ban on selling organs, Mr. Gore told a news conference: "We must not allow technology to dehumanize people so that we erode the distinction between things and people. People should not be regarded as things to be bought and sold like parts of an automobile. If this were

allowed, it would seriously undermine the values of our society."

Mr. Gore said his legislation would establish a National Center for Organ Transplantation within the Public Health Service at the Department of Health and Humane Services. It would be responsible for putting into effect a national program to retrieve and distribute organs.

A national clearinghouse, to be established by the center, would provide a uniform registry of potential transplant recipients. It would also provide for distribution of available organs based on such factors as urgency of need, size, blood and tissue typing and proximity to a transplant center.

The bill would restrict organ transplantation to designated centers, as well as prohibit the sale of human organs.



WHOSE JOB IS IT ?

This is a story about four people named Everybody, Somebody, Anybody and Nobody. There was an important job to be done and Everybody was sure Somebody had done it. Anybody could have done it, but Nobody did it.

Somebody got angry about that because it was Everybody's job. Everybody thought Anybody could do it but Nobody realized that Everybody did not do it. It ended up that Everybody blamed Somebody because Nobody did what Anybody could have done.

Alonzo, at 26 is a 6 year old, but his sculpture is born of genius

Alonzo Clemons still can't read or count. He still can't speak in complete sentences. Occasionally, he must still be reminded to brush his teeth.

But Clemons is no longer just one of the anonymous residents at a group home for retarded adults in Boulder, Colorado.

Now he is Alonzo, one of the hottest young artists in the nation, the "idiot savant," the "retarded genius" whose bronzed sculptures are being snapped up by collectors for hundreds of dollars apiece.

In the four months since his first show, about \$30,000 worth of Alonzo's work has been sold through a Denver art gallery.

He has yet to see a nickel of that money. The people making the financial and artistic decisions for Alonzo — his mother, his lawyer and his art dealer, say they are plowing all his income back into producing more sculpture. And they say they haven't made any money off Alonzo's art, either. At least, not yet.

This is the story of the blossoming of a young artist, one who has a wealth of talent but cannot make his own way in the world. He is 26 years old but has the mental capacities of a 6-year-old. This is the story of the selling of Alonzo.

As long as anyone can remember, Alonzo has been hand-sculpting animals cut out of whatever was at hand. Counselors in the state institution where he grew up used to give Alonzo modeling clay when he was good and take it away when he was bad.

One morning after the clay had been taken away, counselors found tiny black horses under Alonzo's bed. In the night, he had sneaked onto the roof and scraped up tar with his fingernails.

When Alonzo moved to Carmel Ltd., the group home, three years ago, staff members bought him artists' beeswax. Sometimes when he made an especially good sculpture, they took it away from him; otherwise he would flatten it to re-use the wax.

The staff psychologist at Carmel said Alonzo was a classic "idiot savant," from the French for a retarded person with some inexplicable genius in a certain area.

ALONZO'S SCULPTURE IS BORN IN GENIUS

Jim Graves, the Carmel administrator, began taking Alonzo to small art fairs where Alonzo would sculpt horses and cows and Graves would sell them for \$10 or \$20. That money, along with what Alonzo earned as a stableboy at a local ranch, was used to buy a radio and a color television set for his room. And, of course, he bought wax.

Alonzo, who has a quiet, gentle manner and becomes animated only when showing people his work, became popular at Carmel with the staff and the approximately 70 other residents. When Alonzo had plenty of wax, he often gave his friends sculptures, along with a smile and a soul handshake.

Alonzo gave a lot of sculpture to his parents, too, for their home 30 miles away in Denver. His mother, Evelyn, is a bank clerk, his father, O.P., is unable to work because of severe arthritis. A ward of the state since childhood, Alonzo would return home on holidays to visit his parents, brother and two sisters.

Things began changing for Alonzo last February, when an Associated Press story about him brought Carmel 200 letters from as far away as Sweden. Most inquired about how to buy Alonzo's work. His mother used form letters to tell people how to order Alonzo's work, and sent sculptures to those who sent money.

Jack VonEschen, who runs a small western and wildlife art gallery in Boulder, came to Carmel with a proposition. He told Graves he had lined up a foundry that would cast Alonzo's sculptures in bronze but not require payment until they were sold.

An agreement was drawn up. VonEschen and Graves signed it, and Alonzo printed his first name in capital letters. The foundry began casting several of Alonzo's horses.

At about that time, Mrs. Clemons successfully petitioned to be named Alonzo's conservator, putting her in control of her son's finances.

By then, a downtown Denver art dealer, Pam Driscoll, had heard about Alonzo. Driscoll, who sells the work of some of America's best-known Western artists, met with Clemons and both agreed that the bigger, more prestigious Driscoll Gallery would handle Alonzo's work and guide his career.

On Driscoll's recommendation, Clemons hired Earl August Hauck, a prominent Denver attorney and art collector. One of the first things he did was write to Gallery VonEschen, informing Jack VonEschen the Driscoll Gallery was Alonzo's exclusive dealer and suggesting to the Boulder dealer that his contract was invalid because Alonzo is legally incompetent.

Mrs. Clemons, Driscoll and Hauck became what the lawyer called a decision-making triumvirate. They arranged for another foundry to cast Alonzo's work.

They decided no more wax sculptures would be sold, and Hauck sent letters warning people who already owned some that it would be a violation of copyright law to reproduce them. He said he also warned the staff at Carmel not to let anyone see Alonzo or his work without permission from Clemons.

JOB CHANGE

Alonzo quit his job at the ranch so he could devote full-time to sculpting.

Driscoll urged Alonzo to put more action into his sculptures. Standing horses became FIGHTING MUSTANGS, with flying hooves and flaring nostrils. A bear walking in the woods became FATMOUTH AND THE KING, a grizzly with a king salmon in its mouth.

The triumvirate decided Alonzo would sign each sculpture the only way he knew how, with supervision to make sure he didn't print the "z" backward. To keep the value up, they decided no more than 30 castings would be made for each "Alonzo."

Alonzo's first show was in May, and the first copy of his first bronze, CHARGING BULL, sold for \$750. Two dozen more copies of that sculpture have sold since, the last for \$1,200. The Driscoll Gallery took five orders, at \$950 each, for FATMOUTH AND THE KING before it was cast. Alonzo's most recent work, a mare and twin foals, will be priced initially at \$1,500.

Typically, one-third of the sale price for a young artist's work goes to a gallery and two-thirds to the artist. Driscoll said Alonzo has not made any money yet; his share, she said, has gone toward casting new works and paying her back the more than \$10,000 she advanced him for foundry costs.

"Eventually, there will be a profit for Alonzo," she said. "He is making money, but he is putting it all back into casting."

To date, Hauck has billed Clemons \$8,000 in legal fees, taking part of the sum in a CHARGING BULL that now graces his conference room. He said Alonzo's income would eventually pay his fees, along with compensation to Clemons for her "business" trips to the zoo.

Beyond expenses, Clemons said, a trust fund will be established for her son. "Whatever Alonzo wants, that's what I want," she said.

One of the things Alonzo says he wants is a big house in the country where his whole family can live. "With studio," he said, smiling and nodding.

Graves, the Carmel administrator, said of Alonzo's fame, "There's been no ego problem. It hasn't gone to his head."

— Reprinted with permission of

Democrat and Chronicle Rochester, NY



Residents of a community residence in Nassau County gather for a Thanksgiving meal.

Unsealing the adoption records

Each adoption case begins with heart-break and happiness — the anguish of a biological mother giving up a child and the profound joy of an adoptive couple finding one. If the child has any divided feelings, they don't come to the surface for many years, but sometimes adult adoptees want to know more about their biological parents. In such an emotionally precarious situation, what are the rights of adoptees to information, the rights of the biological parents to privacy and the rights of the adoptive parents to the confidentiality and security they thought were guaranteed?

Until the mid-60's, adoption records across the country were firmly sealed. Now there is pressure to open all records, and in three states — Kansas, Pennsylvania and Alabama — it is possible for adult adoptees to obtain their original birth certificates with the names of their biological parents. A more sensible approach, and one that takes into consideration the rights and feelings of other parties in the adoption, is the establishment of registries where sensitive information can be exchanged only with mutual consent. Ten states have established registries, New York just a few weeks ago. The New York statute allows an adoptee over 21 to obtain information about his biological mother only if that woman consented to being identified by filing with the registry. In the case of adoptions completed before April 1984, the consent of the adopting parents is also required; after that date, adopting parents will be on notice that grown children can obtain the information without their consent. The New York law also guarantees all adult adoptees the right to non-identifying information — religion, ethnic, racial and medical background about biological parents — even without mutual consent.

Many adult adoptees will never want to use the registry; many natural parents will never consent to being contacted. And when reunions occur, some will be loving and others disastrous. But an orderly procedure requiring the consent of people whose lives will be altered dramatically by revelation is certainly preferable to a wholesale opening of records that were compiled with the understanding that they were irrevocably sealed. Registries are a sensible and humane approach to a sensitive and emotional subject.

— Baltimore Sun

Support special olympics

MEDICAL INFORMATION

Area 8 Special Olympics has been informed of a new policy regarding Atlantoaxial Dislocation, a condition which has recently been identified by medical professionals in 10 percent of individuals with Down Syndrome.

Atlantoaxial Dislocation is the malalignment of the cervical vertebrae in the neck. This condition exposes individuals with Down Syndrome to the possibility of injury if they participated in activities that hyper-extend or readically flex the neck muscles.

Although to the best of everyone's knowledge not a single individual with Down Syndrome has suffered any significant injury related to atlantoaxial dislocation while participating in Special Olympics training or competition, Special Olympics, Inc. has adopted the following policy which all Special Olympics programs must comply with:

1. Individuals with Down Syndrome shall be temporarily restricted from participation in gymnastics, diving, pentathlon, butterfly stroke in swimming, diving start in swimming, high jump, soccer and any warm up exercises placing undue stress on the head and neck muscles.

2. Athletes with Down Syndrome must be examined for Atlantoaxial Dislocation (including X-ray views of full extension and flexion of neck).

3. Individuals with the condition or those who have not been examined shall be restricted from the activities mentioned above.

We realize this new policy comes with short notice and gives us little time to effectively implement. However, I hope you will agree it comes with good reason. This policy was at the recommendation of eight nationally known physicians, including two neurologists, an orthopedic specialist, a radiologist, and surgeon general, a sports medicine specialist, a pediatrics surgeon and the chairman of the Joseph P. Kennedy, Jr. Foundation Scientific Advisory Board.

As we receive more information regarding this policy, I will keep you informed.

— John Kemmer,
Area 8 Coordinator
Warren-Washington
Chapter ARC

NEWS AND VIEWS EDUCATION COMMITTEE



Tom Scholl shows computer as tool of education.

STATE GIVES AN "A" TO NORTH SYRACUSE SPECIAL ED PROGRAM

We are proud to say that Thomas Scholl, a member of our Education Committee, is a teacher in this North Syracuse School District, and from where we stand, his class contributed to their perfect score.

The North Syracuse School District's special education program has received a perfect score on a recent state audit, according to district officials.

The New York State Education Department audit was conducted by the department's Office for the Education of Children with Handicapping Conditions.

That office's regional associate, Frank Hermon, who performed the audit, described the district's special education programs and services as "outstanding, excellent, impressive, and superior," according to a written statement from the district.

"I wanted you to know how impressed I was with the overall quality of those services, and felt that... you truly deserved to be commended for the outstanding programs that now exist," Hermon wrote to Superintendent Blaise Salerno.

The audit shows the district is in 100 percent compliance with state Education Department regulations, including evaluation of written policies, procedures and classroom practice, Hermon has advised Warren E. Grund, district director of Exceptional Student Education.

A complete audit of the state's school districts' programs for children with handicapping conditions is performed every three years.

Hermon said he is not aware of any other school district in the state receiving a 100 percent compliance rating, the district's statement said.

North Syracuse is the only district in his experience to receive this distinction, Hermon said.

"Our teaching staff, every teacher in this school district, shares in our efforts to educate handicapped students," Grund said.

The district provides special education for 1,046 students, including 108 children in the Riordan Early Education Program.

THE COMPUTER AGE — A new era for handicapped persons: The Education Committee held a very successful workshop on the subject of computers and the person who is handicapped, and we now have six new reprints on this subject:

No. 59 — The Future Is Here.

No. 60 — Computers and Computer Terms; A Brief Explanation.

No. 61 — Computers and Children With Special Needs.

No. 62 — New Voices - Communication Through Technology.

No. 63 — Michigan's PAM Assistance Center - A Comprehensive Resource.

No. 64 — The ABLEDATE System - Instant Information Via Computer.

No. 65 — For More Information - On Computer Resources.

If you did not pick these up at the Education booth at the Convention, ask the State Office for copies. Reproduce them in your newsletters.



Betty Pendler, Chairperson

THERE ARE WAYS TO ACCESS THE WHITE HOUSE AND IT IS IMPORTANT THAT CONSUMERS-PARENTS KNOW AND USE THESE TECHNIQUES

By Betty Pendler

At a White House Briefing, which I attended on behalf of NYSARC, Judy Buckalew, a special assistant to the President, offered some tips and insights on how best to communicate about Education matters to the Reagan Administration.

Ms. Buckalew explained that the staff structure of the White House is headed by the four men whose names are often in the news: James Baker, Edwin Meese, Mike Deaver and William Clark. Next in line are nine persons known as "assistants" to the President. Judy Buckalew is a special assistant in the Office of Public Liaison who deals with handicapped, health, aging, education, environmental and women's issues.

She told this group that she ENCOURAGES INDIVIDUALS AND PARENT — CONSUMER GROUPS to contact the White House. She said, "Think of the White House as a business office and use it as such." She encouraged brief phone calls and explained that often phone calls get more direct service than letters.

PARENTS CAN CALL THE WHITE HOUSE

Ms. Buckalew advised that a productive method of communication is to call the White House, 202-456-1414, and ask for her office, the Office of Public Liaison. That office can then name the specific person in the Office of Policy Development who has the closest connection to the topic about which the caller is concerned. Bob Sweet, a deputy assistant, is the staff person responsible for handicapped issues and he, too, urged that parent — consumers communicate with him.

NOVEL IDEA

A novel idea has been incorporated in a grant by SHARE which will perform education advocacy using people instead of puppets in the school system.

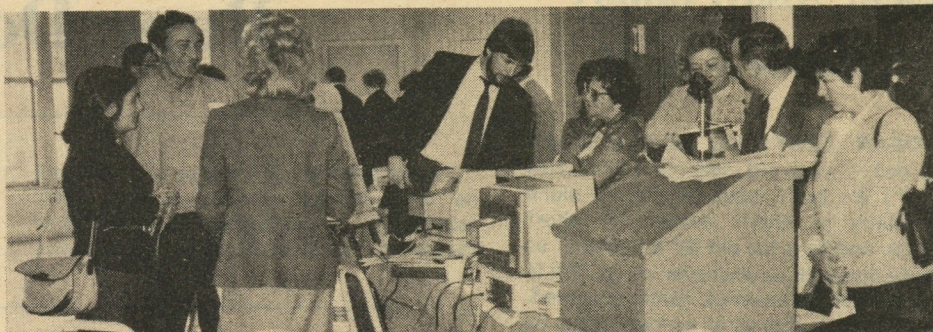
This is a mainstreaming concept we shall hear more about from the Director of the Coordinating Counsel for Handicapped Children. It is a most welcomed and important project and one our Committee hopes to join.

Grumet named to disability planning post

ALBANY — Louis Grumet of Altamont has been named Executive Secretary of the State Developmental Disabilities Planning Council, Gov. Mario M. Cuomo announced in September.

The 24-member Council, that includes the heads of State agencies and private groups, monitors the use of Federal funds for programs aiding the retarded and disabled.

Grumet has served since 1977 as an Assistant Commissioner in the State Education Department for programs affecting handicapped children.



Convention workshop spurs questions.

NYSARC URGES PROTEST

There is a Filing Fee of \$20 to accompany the filing of a petition in an appeal to the Commissioner of Education. At the Convention, a protest resolution was passed, and we urge all parents to write to: Gordon Ambach, Commissioner of Education, State of New York, Albany, New York 12234, protesting the imposition of such a fee. We do not feel that it is in keeping with the provision of a FREE APPROPRIATE EDUCATION under P.L. 94-142, and although the State Education Department states that if a person is unable to pay the filing fee, they will consider an affidavit. We feel this is unfair and illegal. Also, write to: Board of Regents member, and to Mr. Willard A. Genrich, Chancellor, Board of Regents, 4287 Main Street, Buffalo, NY 14226.

EDULETTER: Continues to be published 3-4 times a year with valuable information.

Request from State Office. We welcome items of interest from all.

NEW GUIDELINES AVAILABLE

We distributed one copy of this manual to a Board of Governor's member of your Chapter at the Convention. We sincerely hope that each Chapter will look into activating an Education Committee. The Education Committee of NYSARC will be happy to assist you in this effort. Let us hear from you.

REPRINTS: We hope you will use our reprints to be published in your respective newsletter. This is a way to let the public know that you are ready to give service in educational advocacy.

Some years ago we were visited by a group of European psychiatrists who were in the USA to attend a pow wow and after they looked at our programs, one of them, a young neuro-psychiatrist from Rome, asked me what we were doing about the community and by community he meant public education. When I responded by saying that until an anti-tolerance pill was invented our only tool was education, he made a gesture of deprecation which motivated the female psychiatrist from Vienna to say, "What else is there?" The result was a general discussion among the six or seven people sitting in my office and as might be expected the conclusion was that, inadequate as it is, education is the only tool we have.

By Helen Kaplan,

Executive Director

LETTERS SOURCE IDENTIFIED

The two letters published in the last issue of OCV, "The Sibling Report", were written by the siblings of Michael Shalvey, children of our Education Committee member, Judith Shalvey, 2 George Court, Miller Place, NY 11764. Thank you, Editors.

Suffolk-retarded lose diploma appeal

By Robert Fresco

In a ruling applauded by national educators but condemned by advocates for the retarded, New York's highest court has upheld a lower court order invalidating diplomas awarded in 1979 to two mentally handicapped Northport High School students who failed to pass the state's minimum competency exams.

The ruling, handed down in October by the Court of Appeals, affirms a state law that says high school diplomas cannot be awarded unless students pass the competency exams.

In June, 1979, the Northport-East Northport School District awarded diplomas to Abby Levison, of 104 Gail Ct., who cannot do high-school-level mathematics because of brain damage, and to a retarded boy named in court papers only as "Richard."

Neither had passed the competency test, required by the state for graduation. But both had passed education programs tailored for them by the school district.

Since 1979, the state has provided for awarding of a "certificate of completion" rather than a diploma to mentally handicapped students who have completed an individual course but have not passed the basic competency test. The Court of Appeals decision upheld a ruling last year by the Appellate Division of State Supreme Court, which held that the diplomas should be invalidated.

"I am not happy," said Rosalyn Levison, Abby's mother. "But my comments are really not printable." Richard's family has

chosen to remain anonymous and could not be reached for comment.

The court decision was hailed by Scott Thomson, Executive Director of the National Association of Secondary School Principals. "The diploma should reflect some achievement," he said. It should not mean, he said, that a student has "just warmed a seat."

But Robert Sansone, Executive Director of the Suffolk Association for the Help of Retarded Children, called the decision "a sad thing." The two graduates "will be tainted for the rest of their working lives. How many so-called normal kids get diplomas who barely learn to read?" he asked.

After the diplomas were issued, the State Department of Education ordered them rescinded. The school district sued to allow the students to keep them. In 1981, the district won in State Supreme Court, but the state appealed, and last year the Appellate Division overturned the Supreme Court ruling. This week's decision upheld that ruling.

"We would note that under the circumstances... the petitioning students had no reasonable expectation of receiving high school diplomas without passing competency tests," the seven-member court said in its unanimous decision.

The state will now order the district to formally notify the families of the two students the diplomas are invalid, Education Department attorney James Whitney said.

— Newsday
Garden City, NY

Bid for help or dirty tactics?

Dear Abby, family considers itself

DEAR ABBY: We have a mildly retarded 17-year-old son. (I'll call him "Bill.") We can't leave him home alone (especially at night) except for short periods, and he is too old for a "sitter," so we take him with us wherever we go. Bill is friendly, well-mannered, neatly groomed, and he's not a source of awkwardness or embarrassment to anyone.

OUR PROBLEM: When we are invited to a dinner at someone's house, is it all right to call the hostess and ask if Bill may be included? After all, he's not a small child — he's almost an adult. Sometimes the hostess is a stranger — for example, when we're invited to a wedding and don't know the bride's family.

Most folks, when they learn the situation, are happy to include our son, but occasionally they don't want an extra person. How can we tactfully find out if Bill is welcome?

I might add, if we can't bring Bill, we won't go either.

BILL'S PARENTS

DEAR PARENTS: You say your mildly retarded 17-year-old son can't be left home alone, yet he is too old for a sitter. If he can't be left home alone, regardless of his age, he needs a sitter, and you should make provisions for one rather than take him everywhere with you.

When you call your hostess whom you hardly know and "explain the circumstances," whether she wants an extra person or not, she will find it almost impossible to exclude your son. That's not fair to her.

I know you mean the best for Bill, but he needs a social life of his own, and by denying him one, you are further handicapping him.

Rather than refusing all invitations that do not include Bill, please consider helping him build a life of his own. He will not always have you around to look after him.

From a recent DEAR ABBY column. Copyright, 1983 Universal Press Syndicate. Reprinted with permission. All rights reserved.

— WARC Newsletter

Convention Highlights

The COMMITTEE ON CONVENTION PLANNING (an Ad-Hoc Committee) urged NYSARC convention planners of the future to bring more people from the "grass roots", i.e. parents, community members, persons in other related disciplines to conventions. The Committee suggested scholarships for parents to attend, could be set up in local Chapters. Also between-chapters visiting of Board members and programs was encouraged.

Programs, philosophy, assessments and other related items have been discussed with representatives of the National Association for Retarded Children. Input was requested by President Irene Platt and Executive Director, Marc Brandt, for future talks.

Committees of NYSARC will become part of a Calendar of Activities. Legal and Legislative events take priority, according to the decision of the Board of Governors but all NYSARC Committees which are more active than ever, and whose efforts are constantly being enlarged, need this type of organization internally.

"To go out and get the type of statement he did, in my opinion, was a total fabrication. . . An attorney, as an officer of the court, has a legal obligation to make

evidence known to the court. But that evidence has to be valid and truthful. After our investigation, in our opinion, it was neither truthful nor valid."

— Asst. D.A. Peter S. Blodgett
— By Kathie Barnes
Watertown Daily Times

Rape Defense Sparks Dispute

Atty. Jack Scordo says he was only asking for assistance from the court.

County Judge John V. Aylward says it is improper for a judge to give such advice and suggests that Mr. Scordo's actions in the case were less than professional.

And the district attorney had his assistant say Mr. Scordo at best forced a retarded man to admit a crime he did not commit.

But the fact remains that no one is likely to be convicted of the brutal rape of a 15-year-old city girl last February.

That in itself has made all of the parties to the case angry and has resulted in a war of uncharacteristically strong words from Mr. Scordo, Judge Aylward, Dist. Atty. Lee Clary and Asst. Dist. Atty. Peter S. Blodgett.

Mr. Scordo was assigned in February to represent accused rapist Francis A. Sheltray, 36, of 232 W. Main Street.

A county court jury found Sheltray not guilty of the charges on Sept. 22.

In August, three weeks before the scheduled trial, Mr. Scordo and a private investigator, Howard R. George, elicited from a retarded man with a physical resemblance to Sheltray an admission that he, not Sheltray, was the one who raped the girl.

A lie detector test convinced law enforcement officials a few days later that Lawrence E. Blanchard, 33, of 910 Water Street had lied when he told Mr. Scordo and Mr. George that he attacked the girl on Feb. 21.

Mr. Scordo complains that, in the face of the confession he had obtained from Mr. Blanchard, he was in unknown waters and so he turned to Judge Aylward for guidance on how to proceed.

"I got no satisfaction," the defense attorney said.

"It's not a unique situation," Judge Aylward answered. "Mr. Scordo is a criminal trial lawyer. He should know (what the law says)."

Judge Aylward then sharply criticized Mr. Scordo's conduct in the case:

"This court did not sanction, authorize or approve the manner in which Mr. Scordo and Howard George obtained two different statements from a retarded person like Mr. Blanchard, nor in the manner in which they confronted the young girl witness and her mother in their home. I have no other comment to make about Mr. Scordo's conduct in this case."

Mr. Clary and Mr. Blodgett, have made equally barbed criticisms. They have even implied that Mr. Scordo is guilty of unethical behavior by coercing the confession he obtained and later lying to law enforcement officials.

Mr. Scordo said that, at an Aug. 18 meeting in Judge Aylward's chambers, "I, in effect, was told to go out and get a confession. Judge Aylward told me that. Lee Clary led me to believe if I got a confession, he'd dismiss the charges against my man."

While Judge Aylward admits that he told the defense attorney "a confession would be better evidence than a hearsay statement," Mr. Clary is livid about Mr. Scordo's characterization of his remarks at the same meeting.

"That's absolutely one-hundred percent false. I never told him I would dismiss any charge if he got a confession. I told Mr. Scordo we would consider any confession we got implicating anyone other than Mr. Sheltray."

At that time, Mr. Scordo said he refused to divulge the name of the person who had made an alleged confession because of his mistrust of the Watertown Police Department's handling of the case.

Mr. Blodgett added, "He didn't want to tell us much about what he had. We indicated to him before we would even consider dropping the charges against Sheltray, we wanted to talk to the other person. He was very strongly opposed to the Watertown Police Department conducting the investigation. . . We would not have objected to his being present when a statement was taken (by police) from Larry Blanchard."

Mr. Blodgett continued, "To go out and get the type of statement he did, in my opinion, was a total fabrication. . . An attorney, as an officer of the court, has a legal obligation to make evidence known to the court. But that evidence has to be valid and truthful. After our investigation, in our opinion, it was neither truthful nor valid."

Mr. Clary was removed from the case before the trial at Mr. Scordo's request because he once defended Sheltray, so Mr. Blodgett conducted the trial.

Mr. Scordo asked to be relieved as defense attorney on the grounds he would probably be a witness at the trial, and Atty. William J. McClusky was appointed to try the case.

But Mr. Scordo was never called as a witness because Mr. Blanchard took the witness stand, was granted immunity from prosecution and testified that he made an Aug. 23 confession to Mr. Scordo and Mr. George under coercion.

Legal and ethical questions have since been raised by both sides and all parties have seemed eager to air their criticisms.

Aside from the who-said-what-to-whom controversy, the two sides dispute three areas — the existence of legal precedents in such cases. Mr. Scordo's conduct in taking the statement from Mr. Blanchard and how law enforcement authorities would like to have seen the situation handled.

"I don't know if there is any law on this. I asked other defense attorneys and they said they had never heard of anything like this," Mrs. Scordo said.

Mr. Clary retorted, "He had the same thing with (an arson case last winter where Mr. Scordo alleged someone other than the defendant had confessed to the crime. His client was found not guilty)."

How could it be unique? It's not very ordinary here, but it happens throughout the country."

On the Blanchard statement of Aug. 23, Mr. Scordo says Mr. Blanchard came to his law office voluntarily.

He said Mr. Blanchard denied any involvement until after a visit to the scene of the crime and a later confrontation with a young girl who was a passerby during the rape.

Mr. Scordo admitted that Mr. Blanchard "probably felt he was being pressured" at that time.

After visiting the home of the 14-year-old passerby, Mr. Scordo says, Mr. George informed him that Mr. Blanchard "wanted to confess."

"I called Henry Cumoletti (a legal stenographer)," the defense attorney said. "We had Larry Blanchard read (the victim's) statement out loud to satisfy ourselves that he could read. I felt a question and answer format rather than a narrative would be more accurate, more honest and would meet the test of the court better. Afterward, Larry Blanchard read the transcript of our conversation and he signed it. He was free to leave at any time."

Mr. Clary said, "The story given (by Mr. Blanchard) in the statement did not square at all with what happened. There were major inconsistencies."

Albany shop at capitol

Over the past 4½ years the Hand to Hand Shop run by the Empire State Enterprises for the handicapped has been a showcase for the capabilities of our State's citizens with disabilities. This not-for-profit organization provides both retail and wholesale manufactured, by disabled individuals.

The primary goal of Empire State Enterprises for the disabled is to provide a substantial source of work for individuals with severe disabilities. Since its inception, this organization has provided more than 1,500 work weeks of meaningful, remunerative work for many of our State's citizens with disabilities. Many of our New York State ARC Chapters find outlets for products produced by individuals in their workshops through this source.

HAND TO HAND
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Catalogue available.

On Boxing:

"The object of the whole endeavor is to damage the other guy's brain. It should be removed from the schools."

Dr. Fritz Dreifuss
National Spokesman

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