

Our Children's Voice

Retarded Children Can Be Helped

VOL. XXXV NO. 1

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

JANUARY, 1983

Dialogue

A conversation with our Exec

(Editors Note: Kate Klein, Chairperson of the Public Information Committee, asked for an interview with Executive Director Marc Brandt to satisfy membership curiosity about leadership's expectations.)

Q. As the newly appointed Executive Director of the NYSARC, what do you feel will be your immediate short-term priorities? Should we expect many changes?

A. I have, for the Executive Committee of the Board of Governors, developed a list of short-term priorities which I feel will mark the beginning of my tenure as Executive Director. I see my immediate priority as establishing myself in my new position and to attempt to bring the State ARC to our 64 Chapters. I hope that, within the first year, I will have an opportunity and the time to visit almost all of our Chapters in one capacity or another both formally and informally.

One of my additional short term priorities will be to try to begin to develop a quality assurance component enabling Chapters to call upon our State ARC for assistance in the program areas. I feel that it is most important that our Chapters use our state organization as a resource for program

development and to assist them with their individual advocacy problems. In addition, I feel it is most important that between the technical assistance and the quality assurance which I am hoping our state organization will be able to provide, we will be able to assure ourselves we are truly doing what we all feel we are committed to.

I do not think there will be many radical changes because our state organization has been strong in the areas which are the most critical in assisting the mentally retarded. Any major changes will evolve with the philosophy and thinking of our membership and the collective advice that our Chapters can give through our Board of Governors and the appropriate committees.

Q. What do you feel will be the most pressing problem for you during your first year as the new Executive Director?

A. I think there are a host of problems that will face me as I enter into this new and exciting position. Perhaps, the most difficult situation I face is trying to bring back the credibility to 175 Fifth Avenue that has somewhat eroded over the last couple of years. I feel many of

(Continued on Page 2)



Irene Platt is new State ARC President

By Kate Klein

A heightened sense of mission permeated the 1981 State ARC convention in Niagara Falls as a new president, Irene L. Platt, New York attorney and Marc N. Brandt, new Executive Director took over the reins of leadership from Eleanor C. Pattison.

In his address to the members, Director Marc Brandt pointed out that the State Association must change its course. "I don't feel we need to change in terms of our philosophy or in terms of the commitment that we originally have. I think the change is necessary in order for us to monitor those commitments and to manage those objectives and goals and represent the 64 Chapters and our 35,000 members.

Our State Association must spend a good deal of our resources, our time and commitment in assisting our chapters with their program needs, with their management, but most important, to assure ourselves that the goals and commitments are consistent with the Association's policies for the care of the retarded."

President Irene Platt cautioned the members in her address, "We are all aware of the changes that have taken place in the lives of the mentally retarded through the efforts of this Association. . . but we live in changing and uncertain times. If we are to be sure the positive steps we have accomplished are not lost in the world of fiscal restraints and uncertain public attitudes toward the handicapped, we must constantly maintain our dedication, determination, and participation."

BUSINESS HIGHLIGHT

The Board of Governors approved by the assembly asked for a committee to be appointed to suggest a name change for the Association. The Association Prayer was officially adopted and used for convention.

Committees reported action at all levels. Education Chairperson Betty Pendler told the members "I consider it a compliment to me and the Association that my name is on the Enemies List in Washington because of our opposition to the proposed changes in public education laws."

Prevention Chairman Joan Edwards stated an ambitious goal, namely a substantial reduction of mental retardation and developmental disabilities in children ages 0-6 in New York State by 1990.

The Public Information Committee Chairperson Kate Klein stressed the need for public information policy to be adopted by the Association and a Statewide public information campaign.

Jerome Ness Guardianship Committee Chairperson expressed the need that every resident living in one of the ARC residences should have a guardian. Whether this guardian is a member of the family, a friend, or the Association, someone must be available to act in the best interest of the mentally retarded person.

RESOLUTIONS

— Resolutions passed at convention dealt with opposition to co-location of penal institutions on the grounds of a facility designed to serve the mentally retarded, and a "Bill of Rights" to be established for all residents of Community Residences and for the parents and guardians of such residents.

— A resolution on the dissemination of information about lead poisoning was adopted in the form of proposed legislation for a comprehensive state program to annually test all pre-school children in order to detect and treat children affected by lead.

(Continued on Page 14)

Count members; Members count

New York attorney Irene Platt, newly elected President of the New York State Association For Retarded Children, Inc. stressed the importance of membership's role in the Association to the directors, members and families who attended the convention at Niagara Falls, New York.

"The strength of this Association is the continuous and determined participation and support of our membership in all aspects of the organization's operations", she told the group. It is the mutuality of purpose and effort of the parent and professional that has enabled us to bridge the gap between desires, needs and requisite methods. This has enabled our association to today serve so many retarded people in such a variety of programs."

Irene Platt, the mother of two teenage children, is a partner with her husband in the New York City law firm of Platt and Platt. She was admitted to the New York Bar in 1963 and, during the course of her academic career, was awarded the American Jurisprudence Prize for Excellence in both Administrative Law and Public Law.

Mrs. Platt completed her undergraduate studies at the University of Vermont. She served as a class-room teacher in the Greenwich Connecticut School system for four years.

"We are all aware of the changes that have taken place in the lives of the mentally retarded through the efforts of this Association" President Platt stated. "But

we live in changing and uncertain times, and if we are to insure that the positive steps we have accomplished are not lost in the world of fiscal restraints and uncertain public attitudes toward the handicapped we must constantly maintain our dedication, determination and participation."

"We all have an enormous task ahead of us," she reminded the members, "but we possess the organizational structure and capability with our new leadership, particularly our Executive Director, Marc Brandt, to address the issues that face us."

President Platt's past experience in the Association was as President of the New York League of AHRC 1965-1968; President of the New York City Chapter of NYSARC from 1978-81 and a member of the Board of Governors since 1970. She has served on Guardianship, Budget and Finance, Fund Raising, Planning and Development and Co-chaired the Legal and Legislative Committee prior to her election this year.

"As members of NYSARC we have an obligation to reaffirm our history of dedication and advocacy to and for the mentally retarded of our State. We have an obligation to expand and develop our membership; we have an obligation to represent those we love in all facets of their lives.

As the chain is only as strong as its weakest link, we must insure that membership is not NYSARC's weakest link in our chain of services to the retarded.

DIALOGUE—a conversation with our Exec. from page 1

our Chapters feel our state organization has not been as responsive to their needs and, therefore, do not view the State ARC with either pride or credibility. I hope within my first year to re-establish the credibility of our State ARC once had, and to develop a strong, loud, clear voice for all the mentally retarded of New York State.

I think the strongest need and commitment all of us have in the ARC is to advocate for the needs of the mentally retarded. In order for us to be effective advocates, we must assure each other that we are truly meeting the needs of the mentally retarded both in the community and in the institution and we must effectively stand together as one voice for the mentally retarded.

One of our pressing needs is to provide to our Chapters technical assistance in a variety of areas due to the complexity of our funding mechanisms and the changing rules and regulations with which all of us are faced. I hope that, within a relatively short time, I will be able to set up, with help and assistance of many of the local board members and professional staff, a technical assistance format which will enable our State ARC to effectively help our local Chapters with their programs and financial operations.

Q. Almost four decades ago, parents formed an association and bought a dream of better life for children and adults who are mentally retarded. In these changing times, and given the realities of compromise, what do you believe parents now expect from NYSARC? Also: What do you think parents within the association should expect from each other?

A. The complexity and scope of the New York State ARC has certainly changed over the past four decades. I firmly believe, however, that the initial goals, objectives and commitments of the original founders is still at the very heart of what the parents today want and desire from the State ARC.

I believe in its simplest form, it can be stated that the parents of the mentally retarded desire for their child the same rights, the same protection, and the same opportunities that are available to all children in New York State.

We have seen in the last several years many gains and a great deal of improvement in the quality of life of the mentally retarded of our state. Many of these accomplishments have been achieved by the direct involvement of the hundreds of parents and interested individuals who serve on the Boards of the local chapters of NYSARC.

I truly believe that what parents want today is a common voice in their State Association to protect the many accomplishments that we have collectively received on behalf of the mentally retarded, and to advocate for needs as yet unmet. As our programs develop in local Chapters, the need for technical assistance and quality assurance is more and more apparent. As I travel across our state, visiting a number of our Chapters, I sense that our parents need and want a direction and deeper involvement in their child's programming. This, of course, can only be accomplished if parents become actively involved in their Chapters, which really is the goal of our organization.

I hope parents will continually seek out each other. It has always been apparent to me that one of the unique strengths of our association resides in our parent power. I hope that parents continually assist each other, as they have over the past 40 years, in the development and growth of our state organization.

Q. What do you think people with authority over a citizen's life in home towns across the state — professionals such as clergy, doctors and others, for instance, the police — and School Board members should contribute toward developing a truly interacting relationship with the children and adults who are mentally retarded who live in their home towns? Discuss how local chapters should work with these "authorities".

A. Over the past several decades, as an association, we have been most effective in securing needed legislation and a number of laws which now protect the rights of all the handicapped.

Beyond any law or piece of legislation, I feel it is the moral obligation of society to assist those individuals who need additional guidance due to a handicapping condition beyond control. Although it has become the legal responsibility of many individuals with authority to protect the rights of the retarded, it should be that society has this obligation and should accept it without any additional concern or delay. The involvement of our local chapters becomes critical if we are to appropriately address the issues of advocacy for the mentally retarded in our local communities.

Philosophies, goals and objectives of our State Association can only be implemented, and are only as strong as is the strength of our local chapter level to educate the public to recognize the potential of individuals who are mentally retarded. The capabilities of the mentally retarded can best be demonstrated in our home towns of New York State through advocacy and educational efforts by our local chapters. To this extent, one of my first priorities in assuming the position of Executive Director of the New York State ARC will be to work with our local chapters in enlarging our role and effectiveness all across our state.

Q. The frame of reference "Mentally Retarded" comprises many different levels of potential. The range from unaware to confused, to comprehension — to communication and, finally, interacting can be limited by a person's potential anywhere along the developmental sequence. Do you anticipate new kinds of needs assessment procedures to deal with these specifics?

A. I feel very strongly that there must be an identifiable continuum developed in each of our Chapters so that a mentally retarded person can appropriately achieve his or her full potential within the continuum. We have, over the past several years, developed many services for the mentally retarded. However, as all too often is the problem, individuals can get lost within the system unless they have been properly assessed as to what part of the service system they are ready for, or capable of, in achieving success. Probably, over the next several years, there will be many new kinds of assessment procedures developed. I do feel, however, that the need at this point is not so much for development of assessment tools, but rather a reassessment of the programs and services we currently have available. To this end, one of my early priorities will be the development of a system to assure both the quality and appropriateness of programs and services.

Q. Community based services represent our association's victory over community apathy. What do you believe, answering from the present realities, that children who are mentally retarded have a right to expect from their parents and relatives?

A. The answer to this question is rather simple for me. I believe that no matter what the realities are, children who are mentally retarded have every right to expect from their parents and relatives the same privileges and enjoyment of life and tranquil assurances of love that every child expects from their parents whether they are retarded or not. True, a child who is mentally retarded needs additional assistance and guidance from his or her parents and relatives. But we have more than documented through our association, the child who is mentally retarded whether the child be at home or in an alternate setting, has the same right as the child who is not mentally retarded and, therefore, should have the opportunity to grow and develop and to be loved that is afforded to any other child.

The NYSARC Guardianship Committee under the new leadership of Chairman, Jerome M. Ness, Esq. wishes to extend an open invitation to chapters and other interested groups, to have a representative of the committee speak to you on the subject of Guardianship.

All inquiries pertaining to guardianship should be directed to the attention of:

Jerome M. Ness, Esq.
Chairman, NYSARC
Guardianship Committee
175 Fifth Avenue Room 1000
New York, New York 10010
Phone: (212) 674-1520

SUPPORT YOUR LOCAL CHAPTER

Where the Action is

Congressional Budget Timetable

Nov. 10	Current services budget submitted
15 days after Congress convenes	President's budget submitted
March 15	Committees submit budget reports to Budget Committees
April 1	Congressional Budget Office sends report to Budget Committees
April 15	Budget Committees report first budget resolution to House and Senate
May 15	All authorization bills reported
May 15	Final action on first budget resolution
7 days after Labor Day	Final action on appropriations bills
Sept. 15	Final action on second budget resolution
Sept. 25	Final action on budget reconciliation measure
Oct. 1	Fiscal year begins.

Our Children's Voice

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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

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President: Irene L. Platt

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Please address all inquiries to:

New York State Association for Retarded Children
175 Fifth Avenue
New York, New York 10010
212-674-1520

(Editor Note: Advocacy is not suppression of sincere opinions but fair airing of conflicting views.)

Dear Editor:

Several weeks have gone by since I first read Mr. Weingold's letter printed in the last issue of "Our Children's Voice". Even today I find it almost impossible to put into words my feeling of horror at what he wrote.

With great restraint I will not allow myself to once again go into great detail about my own personal feelings regarding what I consider to be the merciless killing of an infant who had the misfortune to be born to parents who for whatever reason felt there was justification for allowing a helpless baby to starve to death.

I will not even go into detail over the shock I felt in reading Mr. Weingold's statement regarding the action taken by our Board of Governors. My own personal feeling was that the Board and/or our Association did not take a strong enough stand.

Mr. Weingold, as does any other individual, has the right to his own feelings. I will say, however, that I feel pity for him that he believes that having a child with Down's Syndrome in one's family is "to assume the life long terrible burden of the care of such a child". My outrage is for those who are charged with the responsibility of seeing that "Our Children's Voice" is a paper that speaks out in a positive, enlightening way to parents and other members of our communities on behalf of our sons and daughters who perhaps cannot speak for themselves. Many of us have written letters to newspapers over the years and for a variety of reasons, have not seen them in print. Letters are selected as the discretion of the editor. I cannot understand what good purpose Mr. Weingold's letter could possibly serve. In fact, his letter has done a disservice to the population of people our Association is committed to serve.

I hope, in the future, that those responsible for selecting the content of "Our Children's Voice" see their role as advocates for those with mental retardation and not allow the newspaper to be used as a catharsis for any one person's emotions.

Sincerely,
Marilyn R. Wessels
Schenectady, New York

Dear Editor:

Although the Indiana court ruled in favor of the decision made by his parents, there are no winners in the tragic story of Baby Doe. The Board of the New York State Association for Retarded Children passed, on May 1, 1982, a moderate, sensitive resolution protesting that court decision. The statement was entirely consistent with NYSARC's mission as an advocate for the retarded.

Our Children's Voice, NYSARC's publication, is to be congratulated for printing opposing views on the Baby Doe case (September 1982 issue), but one in particular, by Joseph T. Weingold, is an insult to readers of Our Children's Voice.

- Has Mr. Weingold not learned that "Mongoloid" is an inaccurate, unscientific, and unacceptable term?
- The resolution nowhere "condemns" either parents or court.
- NYSARC correctly used the word "infanticide." An individual who is intentionally starved to death is murdered, whether in a hospital or in a slum.

The issues raised by the Baby Doe case did not die with the infant. But it will take another Baby Doe to bring the issue to the U.S. Supreme Court. Many Baby Does are born and die each week in this country. A courageous person, supported by organizations like NYSARC, will someday challenge these secret life and death decisions. This needs to be adjudicated by law and logic, not personal or public convenience.

FORUM

The Editors welcome letters on issues. Please refrain from personal attack letters. All letters must be signed.

Most of us agree with the late Chancellor Kibbe and Mr. Weingold; there is too much arrogance and simplemindedness in the world. However, Mr. Weingold applies the Chancellor's plea for more compassion only to the parents. What about the infants? Do they not deserve compassion?

NYSARC, and similar organizations show true compassion and "an appreciation of the complexities" of life by providing alternatives for these children and their distraught parents.

Unfortunately, Mr. Weingold missed the point.

Very Truly yours,
Carol B. Fitzgerald
Corresponding Secretary
Parents Assistance Committee
on Down's Syndrome

MORE ON BABY DOE

Dear Editor:

While I am completely opposed to any form of euthanasia, I have some concerns about reactions to the Baby Doe case. We ARC members see living proof of the rightness of keeping Down's Syndrome children alive. Just being born with Down's Syndrome is not justification for refusing life saving surgery to an infant. However, are we generalizing beyond our knowledge? I tried to be knowledgeable about Baby Doe as it happened; but the emotionalism of many articles left me with numerous unanswered questions. I ask these questions as a parent who could have faced a similar situation four years ago. I lost, through spontaneous abortion, a child with a trisomy and other defects. I would have asked these questions had Baby Doe been mine.

1. Does this child have a reasonable chance to live through this surgery?
2. Will this surgery allow this child to live a reasonably pain free life?
3. Are there other physical defects which will require multiple surgeries?
4. Will this mean the child's existence will be a living torture to this child?
5. Have I obtained several opinions about this child's condition?

I feel the parents of a child born with multiple defects must, with the help of their support systems, evaluate their situation. If the child can not live, in spite of our best efforts, then let us support him and his family in death. I can not condemn the parents of Baby Doe as I don't know the medical facts which led to their choice. I do feel we, as an Association, should take this situation as a call to educate the public to the potential of the mentally retarded. We should also get back to one of our founding purposes, being a support group for each other. We may not agree with them; we can still give them the emotional support they need when faced with a horrendous decision. We can say we want retarded children to have life, but if that is not possible, we will give our support in death.

Sincerely,
Martl Smith
Erie Chapter

THANKS FROM OTSAR

Dear Editor:

I am the appreciative parent of a three year old who attends the AHRC (Blue Feather) Pre-School Program in Brooklyn. I am also an avid reader of Our Children's Voice.

I would like to highly praise your informative newspaper. I especially enjoyed your full-page even-handed coverage of the sensitive Baby Doe issue.

May I also inform your readers that there is a recently formed parent organization called OTSAR (Hebrew for Treasure)! We are a self-help group giving comfort and reassurance, information and services to Orthodox parents of retarded children.

Have a very successful year.

Yours sincerely,
Mrs. S. Zakon
Brooklyn, New York

SUNMOUNT TO TAKE BIDS

Dear Editor:

We asked Joseph T. Weingold to comment on this article. We appreciate including both the article and comment in FORUM.

— Public Information Committee.

Deputy Director James Westerfield, Sunmount Developmental Center, announced in October that advertising for bids for the construction of two Intermediate Care Facilities to be located on the grounds will appear in local newspapers in the near future.

Approval for the construction was gained when Zygmund Slezak, Commissioner of State's Office of Mental Retardation and Developmental Disabilities, overrode a recommendation for rejection by the Health Systems Agency of Northeastern New York.

The move has been opposed by Klaus Meissner, executive director of the Franklin County Association for Retarded Children, who wanted the units located outside the Sunmount grounds.

The two units will house 11 and 14 patients. Renovation and construction to the two buildings, formerly occupied by the Sunmount Center professional staff and their families, is expected to be completed sometime late in March 1983.

COMMENT: This is an obvious attempt to circumvent the Site Selection Law; more it is a cynical perversion of the principle of "least restrictive environment".

Surely these are intended as "group homes" but hardly "community residences" in any acceptable meaning of the word community.

It seems to us that the Board of Visitors and the Parents Group at Sunmount should be up in arms against this move. It is not that we object to buildings of less population density. But to confuse this issue by calling them Intermediate Care Facilities confused with community residences, as if they were outside the walls of Sunmount, is immoral, to say the least.

In addition, the reference to "11 to 14 patients" is appallingly reminiscent of the dark ages in referring to people who are mentally retarded as "patients".

CLIENTS OR NOT?

(Editors Comment: Webster also defines client as one under the protection of another; a dependent.)

To The Editor:

It is with great disappointment that I find myself writing this letter.

As a member of ARC for 10 years, I have always enjoyed reading Our Children's Voice, finding it very informative and educational. I have always felt that ARC was THE advocate for the retarded.

However, I am disappointed with your advocacy and terminology. What I am referring to is the way you address the men, women, and children that are retarded. Your choice of the word

"CLIENT" (page 11 — "Gladys Ozga honored", a wonderful person, would have been a better article if the word "client", which was mentioned 18 times, was eliminated) does not bring to my mind a person that is retarded.

For the record, according to Webster's Dictionary, the word "CLIENT" is defined as a person or company in whose behalf a lawyer, or accountant, etc. acts; or a customer.

As a parent of a child that is retarded, I find myself appalled and humiliated that an organization that deals with people that are retarded, refers to them as "clients." Even though these human beings are retarded, they are people first. If a person wears glasses, or is left-handed would you refer to them as "clients"? They too, are considered handicapped.

At a time when advocacy is of the utmost importance, how do you expect the general public to react to the retarded when the very organization that was founded by concerned parents and friends cannot use the proper dignified words to describe those people that are retarded?

If I had my way, the word "CLIENT" would be deleted from the human services field.

As a point of interest, it is refreshing to know that in other places, out of N.Y., the retarded are referred to as men, women, and children.

Your truly,
Fran Smolen
3 Oak Ridge Road
Pomona, N.Y. 10970
September 29, 1982

ARC WITHOUT PARENTS IS AN "AGENCY"

Dear Editor,

I have now had occasion for over a year to observe the path of ARC from the sidelines, as it were.

Unencumbered by the day to day trivia of operation, the broad movement can be seen, including the smaller tributaries, either moving or stagnant.

What stands out, more than anything else, is the absolute dependence of our chapters on the State largesse. Although this recognizes society's obligation to the less fortunate, it also fosters a debilitating dependence. It undermines initiative (as evidence in the decrease in fund raising efforts in most chapters) and places the retarded in dire peril, subject entirely to governmental whims.

Another aspect that fills me with apprehension is the increased reliance on management for management's sake. What ever happened to the retarded? Is it enough to label them "citizens" and then not get them all the rights and privileges of "citizens" — or even resident aliens?

Their welfare, in every sense of the word must be the primary concern of our organization, without hedging, without compromise.

If we are not advocates, we are nothing but bookkeepers. The welfare of the retarded person must supercede considerations of staff convenience, state convenience, Board convenience and even Executive Directors' annoyance.

Even though the ship may not be as taut as some would wish, more power must be given to the parents for uncensored (any, without reprisals) input on programs. Who are we to say: "We know best." From what I have seen in a number of our programs, we do not know best; in fact, we do not know well — we know badly!

This organization was built by parents — certainly with help — but parents were the moving force. Remove them and you have what we are being labeled, an "agency".

Sincerely,
Joseph T. Weingold

Acceptance Teaching

Caught as we are between the need to have our home town communities accept the presence and personhood of our sons and daughters who are mentally retarded and the need for our children and adults to accept themselves as people first, handicapped second, (in the various categories of mental disability and their combinations) it is no wonder that parents often feel unsure of their own feelings about what is right or wrong in this kind of person-to-person education.

Aside from this dilemma -- first priority is the parents own needs to deal with the demands on family that the presence of a child with a handicap continually makes. Each stage of growth of the infant to child to adult brings new varieties of demands on parents to cope and learn and grow to the needs.

So when I read a manual devised by Senior Social Worker Madeline Greenbaum and Sandra J. Noll, Developmental Disabilities Specialist entitled "Education for Adulthood" the idea of sharing what impressed me in its content became important even though I have not attended any of the sessions prepared for in the manual.

Ordinarily I expect manuals to be loaded with technical terms which shut out understanding by a casual reader but this one is laced with easily understood instruction in its curriculum for the mentally retarded who need a better understanding of life's processes. The manual and its innovative program design was sponsored by the Staten Island Mental Health Society Center for Developmental Disabilities.

EXPERTS MOVED BY DISTRESS

In a telephone interview with Dr. Greenbaum we learned that aside from the obvious topic need of the program, people working with the mentally retarded in the many facets of preparation for life say the saddest, most difficult aspect of reality training is helping the mentally retarded to accept the handicap of mental retardation.

"Most teachers would rather deal with difficult sexuality cognition than the often painful struggle of mentally retarded young people to learn about their own disability," Dr. Greenbaum stated.

JOINING THE HUMAN RACE: FINDING YOUR OWN PACE

With the authors' permission we excerpted the crucial segment dealing with reality testing to determine what is appropriate handicap by the person who is mentally retarded.

Although the EDUCATION FOR ADULTHOOD manual was designed for people leaving the institution and going into what the state defines as "community" namely, community residences or Intermediate Care Facilities or even foster care, the honest, benevolent approach to the problem of acceptance of a handicap by the person who is so handicapped could well benefit those who never left family life environment. Dialogue between teacher - leader and students could easily be reproduced on a person-to-person level between parent and family member.

Goals set for this session include identifying (by the person who is mentally retarded) the basic physical, emotional and mental handicaps. Then, development of understanding of the ways mental retardation influences a person's life is discussed. Next, people in the session identify ways in which people react to the mentally retarded on the basis of that handicap. Following this there is a portion of the session devoted to common causes for such a handicap.

Understanding the feelings of all people who are handicapped is an important part of this session and also (of particular interest to parents) the ways to identify people with whom such handicapped people can talk about their feelings and problems.

THE GIST OF IT ALL

Greenbaum and Noll in their introduction for teachers of sessions explain "Students will have difficulty identifying themselves as people who have handicaps, especially the handicap of mental retardation."

Some may not know what that term means. Some may say they are slow or have a learning problem. Some may know and be angry. Many will deny it. Acknowledging physical handicaps is often far easier than acknowledging the handicap of mental retardation because of the stigma society attaches to mental retardation."

HARD TELLING

They caution the teacher-leader: "Perhaps you will have difficulty telling the students they are mentally retarded. If you are to help them, it is important to do just this so they can understand why they are in a workshop and not employed in an office, teaching or becoming a doctor. Hopefully, this honest, benevolent approach will reduce their frustration and some of the shame and anger with which they live. Remember, our job is to find realistic ways to live with their handicap."

"I WISH PEOPLE WOULD STOP SAYING RETARDED. I AM A PERSON!"

The above statement has been a plea for understanding from many young adults with whom I have talked. It is a frustrating experience to be considered a handicap first and a person second. For people leaving an institution to go into a community or indeed for an adult leaving home to take part in workshop life for the first time (as shown in the documentary "Best Boy") the feelings about such changes are difficult to assess, (even as shown in the film) because the people involved are not used to telling their feelings to each other.

Greenbaum and Noll explain how difficult it is to teach abstractions like feelings to the mentally retarded. "Mainly because in institutional care adults who are mentally retarded have grown up in environments where caretakers saw their responsibilities as limited to care alone. These environments punished individuals who expressed feelings and asserted themselves. They also suppressed individuality and fostered dependence." A caution to the leader-teacher in the sessions about acceptance is: "As the students are being asked to discuss handicaps and to see themselves as handicapped people, it is important that they never lose sight of being people first. Limited in certain areas by their handicaps, they should be helped to develop a sense of what they can do, as well as what they cannot do."

BUT HOW?

"Students should be lead into being able to describe a handicap (disability) as a condition that makes it harder for people to do certain things and/or not possible for them to do certain things. They should be led into giving an example of a physical or mental or emotional handicap; also to be able to identify two common causes for handicaps. Then acknowledge their own handicap.

The leader-teacher will: Develop an understanding of a handicap; also explain that handicap and disability mean the same. A person with a handicap is someone who cannot do certain things most other people can do. A person who can do things without difficulty is called normal. People can be normal in some ways and handicapped in others. Not all handicaps can be seen.

Some handicaps last a short time and some never go away. A handicap is not contagious. Several people in one family can have the same handicap. A handicap is not something to be ashamed of.

Having a handicap does not mean you



EVERYTHING'S COMING UP GREEN at the Nassau AHRC greenhouse where that chapter's horticulture program regularly sells about a thousand Christmas wreaths along with assorted ornamental greens and poinsettia plants to the public. Lots of green goes out but plenty comes back as the wreaths are a sellout every year.

A new voice

BY GUNNAR DYBWAD, PH.D.

There is a new voice in the world of mental retardation, a little unsure but steadily gaining strength. It is the voice of mentally retarded people themselves - those once considered uneducable, who now attend schools; those once determined unemployable, who now bring home paychecks.

I am gratified to know that mentally retarded people participate in deliberations that affect them. They have begun to manage discussions, learn how to vote, conduct meetings, abide by group decisions. They have begun to make critical reactions to the well-meaning programs designed for them.

Readers may comment: "This may be possible for those who are mildly handicapped but surely for the majority this is an impossible dream." No more impossible than the dream that mentally retarded persons can go to school, gain acceptance in the community, learn to make responsible choices.

Twenty years ago at a conference of special educators a parent asked: "Why do you always say that our severely handicapped children cannot learn?" Those questions still hold true.

Let us not argue how soon or how many of our young people will be able to express themselves. Let us instead ask ourselves: Are we ready to listen to their new voice?

The above article originally appeared in **NEWS**, a publication of the International League of Societies for the Mentally Handicapped. It came to us via **NEWSLETTER** from the President's Committee on Employment of the Handicapped.

are not good and lovable person."

I hope to report on another portion of the manual in a future issue of *Our Children's Voice*. In the meantime, three cheers for Madeline Greenbaum and Sandra Noll! Never let it be said that words failed us.

Literature for siblings

The Sibling Information network recommends a new book for children, teachers and all other professionals. It is a book about special needs. . . "What If You Could Not?" and was reviewed for the Sibling Network by Irene Q. Powell, Community - Coordinator for the Tolland Area Association for the Retarded and Handicapped, Inc. in Vernon, Connecticut.

The emphasis in this book is on people first, handicapped second. It does not ask the reader to imagine what it is like for someone else to have a particular handicapping condition, but speaks in the second person. This is an important consideration when you stop to realize that handicapping conditions may be acquired by anyone, at anytime.

This book is authored by Janet Kamien, of the Children's Museum of Boston, and came about as the result of a special needs exhibit at the Museum. Ms. Kamien engages the reader in a personal dialogue, offering examples and anecdotes from her own experiences.

In the beginning of the book she sets the tone with a comment, made with hindsight, on the effects of the segregated and "hidden" special education classrooms she recalls from her childhood:

It is hard to learn and grow and feel happy when a lot of the people around you are ignoring you or making fun of you. There is nothing wrong with a special class if you need extra help in school, but a special class that makes you feel different and bad about yourself will not help you much.

Retardation, visual and hearing impairments, physical disabilities, learning disabilities and emotional disturbances are each covered in a separate chapter. Facts are presented. Situations are described to stimulate critical thinking. Activities are suggested which stimulate various aspects of a particular handicap, and controversial issues are covered in an unbiased manner. This book can easily be a beneficial tool with groups of children investigating disabilities or as a spring board with siblings' groups.

Supplementary Security Income

Why people are losing their benefits and what they can do about it

By James Flanagan, Executive Director Rensselaer ARC

The past year has seen a sharp increase in the number of mentally retarded adults who have either lost their eligibility for SSI benefits or been denied that eligibility upon their first application. Before we go into the details as to the methods being used for these denials and the techniques that can be used to appeal unfavorable decisions, we should first define several terms:

SSI — The Supplemental Security Income Program, which is designed to provide assistance to aged, blind and disabled people who met certain eligibility standards.

SSDI — Social Security Disability Insurance is a program for which many mentally retarded adults are also eligible. In cases where the parent of the mentally retarded adult is deceased, disabled or retired and has achieved eligibility for Social Security, the son or daughter who is mentally retarded may receive SSDI benefits. In addition, a growing number of mentally retarded adults who have worked for a period of time are now eligible for SSDI.

Disability Determination — This is a process by which the Social Security Administration does an initial review to determine that the applicant meets the disability standards established for receiving benefits.

Continuing Disability Interview (CDI) — After a recipient has received SSI or SSDI for a period of time, the Social Security Administration may come back and review their case to determine that they still meet the standards of eligibility for benefits.

During the past year the number of rejections experienced by both SSI and SSDI applicants upon initial disability determination have increased dramatically. In addition, the pace of continuing disability interviews for SSDI recipients has increased dramatically. There have been further indications that the Social Security Administration is planning more intensive continuing disability interviews for SSI recipients.

What all this means is that people applying for these benefits or wishing to retain these benefits are having their cases reviewed more thoroughly and more often. Unfortunately, in many cases the disability determination or continuing disability interview is negative, with the onus placed on the applicant to prove that the determination was incorrect. In most cases these negative determinations are made by a person who has never seen the applicant and who has been under increasing pressure in recent months to make negative determinations.

To understand the method used most often to make negative determinations, it is necessary to define one more term. **Substantial Gainful Activity (SGA)** is a term which means that the individual is able to do productive work which requires some physical or mental skills and for which the individual is, or could be, paid. If a person is capable of Substantial Gainful Activity, they are not eligible for benefits.

When the SSI Program first started, an arbitrary test of Substantial Gainful Activity was used. Social Security Administration felt that a person was capable of SGA if they earned \$200 or more per month. This led to many problems, as trainees in vocational rehabilitation programs would try to avoid going over the magic \$200 cut off point, which would cost them their benefits. As a result, the

SGA test actually served as a work disincentive, discouraging many people from making progress in their rehabilitation programs. Through the efforts of people like Senator Daniel Moynihan and Congressman Thomas Downey, the Social Security Amendments of 1980 removed this particular work disincentive.

The Social Security Administration has now found a new technique to deny benefits based on substantial gainful activity. A disability examiner, who just about never sees the applicant, takes whatever information is available regarding the training and experience of the applicant. The examiner then picks three relatively simple jobs from the Dictionary of Occupational Titles which he claims the applicant can perform. Among the more common jobs picked from the Dictionary of Occupational Titles are cuff folders, clock winders, pillow stuffers, stackers, banders and assemblers. The Disability Examiner claims that the applicants can do these jobs and are not disabled and therefore not eligible for either SSI or SSDI benefits. While many of the jobs listed in this type of disability determination are the kind commonly used for vocational placement of mentally retarded adults, anyone who has ever been involved in job placement knows the process is hardly this simple. There are many other factors which have been completely ignored by the Disability Examiner. Unfortunately, most applicants and their representatives never even see the documentation upon which the negative determination was based and are not even aware that such a form exists.

In order to appeal the negative determination, whether it be an initial disability determination or a continuing disability interview, the individual or his representative should take the following steps:

1. Go to the local office of the Social Security Administration to review the individual's file and see the basis upon which the disability determination or continuing disability interview was based. Usually this information is contained on a form titled Disability Determination and Transmittal (Form SSA-831-U5) or on a Continuation Sheet (Form SSA-834-U5).

2. The individual applicant, parents or advocate can also bring along a representative to assist in reviewing the file. Sometimes an attorney can be helpful if the determination is based on a legal point. However, most often it is based on an interpretation of the person's disability (or ability to engage in Substantial Gainful Activity), which can best be reviewed by a Rehabilitation Counselor who has worked directly with the individual applicant. In any event, you have a right to request and receive copies of all materials in the person's file.

3. If you find that the technique of taking three jobs from the Dictionary of Occupational Titles has been used you can respond to the determination using a statement from a Rehabilitation Counselor or other individual with credentials in the rehabilitation field. You cannot argue that there are no openings in your community at the present time in the specific job areas suggested by the Disability Examiner. Instead, you should try to show that the applicant has no experience in any of the suggested jobs, has none of the skills that will be needed in the new jobs or would have to be retrained to do the new type of work. In addition, you may wish to have the Rehabilitation Counselor use in-

formation from the person's case records to point up general problems which would make it difficult for that person to find any work in a competitive position at the present time. This might include information on difficulty attending to task, easy distractibility, problems responding to supervisor or low productivity compared to competitive norms.

4. You are entitled to an appeal, then a reconsideration and then a hearing. You should be sure that all these steps are done on a timely manner. For example, if you are allowed 60 days to submit an appeal you must submit the appeal during that period of time or the benefits you receive will not be retroactive to the initial application date. If you have 30 days to request a hearing, it is important that you file that request within the designated period of time. Often it will take the Social Security Administration anywhere from six to eight months to actually conduct the hearing. However, if all requests have been made on a timely basis, and you are eventually successful, you'll receive payment retroactive to the initial date of application.

5. You should not be discouraged if you are unsuccessful at the appeal and reconsideration levels. These steps are essentially completed by people whose ability to interpret the law is very limited. Most ARC Chapters have found that their success rate increases significantly when they get to the hearings level and present their case to an administrative law judge.

6. You may request assistance from an attorney or rehabilitation counselor familiar with the individual applicant. It is strongly suggested that people obtain such assistance when going through the process for the first time.

Unfortunately, one of the methods used to cut Federal spending over the past year has involved the systematic denial of benefits such as SSI and SSDI, while placing the onus on the parents or friends of the individual applicant to prove that the decision of the Social Security Administration was wrong. You are encouraged to take advantage of the various appeals, reconsiderations and hearings available to you to see to it that you do not fall victim to this process.

Parents resort to legalities

A profoundly retarded 25-year-old woman will be permitted to receive an abortion if her parents consent, a judge has ruled.

"She wouldn't understand the pain," said the father of the retarded woman, who has the mental capacity of an 18-month-old infant.

Acting State Supreme Court Justice William Deeley had denied the petition when it was presented to him Sept. 9 by the Brooklyn Developmental Center, who sought the operation with permission of the woman's parents.

They originally claimed an abortion should be allowed because pregnancy was a threat to the woman's life. Deeley rejected that argument but ordered a rehearing Wednesday at the request of the state attorney general.

The attorney general's office argued the woman's parents could consent to the abortion because she was not competent.

Collection alert

The Social Security Administration as well as other federal agencies have been directed to emphasize their debt collection efforts. The House and the Senate have recently passed a bill that will help the government collect \$40 billion owed it by various debtors. Of this \$40 billion, \$3 billion is overpayments to beneficiaries of federal programs. The Social Security Administration is entrusted with taxpayers' money. The money owed because of overpayments is money owed to the taxpayers. Should this money owed go uncollected?

Supplemental Security Income (SSI) is a federal program that pays monthly checks to aged, blind, and disabled people who have limited income and assets. It is a needs program. Factors such as living arrangements, resources, income, and citizenship determine the amount of payments due and whether or not a person is eligible for payment.

People who receive SSI payments have an important responsibility to report any change in their circumstances which could affect the amount of their payment. Any change in the above factors of eligibility will have an effect on how much they can receive in SSI payments. Much of the overpaid amounts in SSI results from the failure of recipients in reporting changes.

The law requires that Social Security and SSI overpayments be paid back unless recovery of the overpayment may be waived. We are aware that repayment of overpayments may present a hardship in many cases and our agency is sympathetic to these hardships.

People who are overpaid have certain appeal rights. Recovery of an overpayment may be waived only if the person is not at fault in connection with the overpayment and recovery would deprive that person of income necessary to meet his or her ordinary living expenses or would otherwise be unfair. People must contact Social Security to file a request for a waiver.

If a request for a waiver is denied, a person can ask for a reconsideration of the case. If not satisfied with this decision, then he can request a hearing before an administrative law judge. If the hearing request is denied, a request for an appeals council review can be made. The last step of the appeals process is the filing of a civil action in the U.S. District Court.

However, many people upon being notified of an overpayment tend to ignore our requests for repayment and do not contact Social Security to make arrangements for repayment or to file an appeal. Then we are charged with harassing tactics in our efforts to resolve the overpayment and to collect the money owed. Should we stop our efforts to collect this money? How long would The Times or any other business survive if they did not attempt to collect money owed to them?

Social Security has a number of booklets which explain, in detail, changes in circumstances that should be reported to make sure an overpayment is avoided. Also, information about the appeals process and overpayments and how they can be repaid can be obtained from your local Social Security office.

Field Representative Statement, Timothy J. Maloney

Kids cause collisions

A study by the University of North Carolina Highway Safety Research Center documents that unrestrained children in automobiles can and do cause collisions, reports the Patriot and Free Press of Cuba, N.Y.

It was determined that, in a five year period in the United States, there were at least 748 accidents in which unrestrained children (up to the age of 12) were at least a contributing factor to the cause of the crash.

National Spokesman

Changes in SSI program

Several important changes have been made in the supplemental security income (SSI) program by a new law, Sanford C. Gross, Social Security district manager in Watertown, said recently. The changes include:

Proration of first SSI payment: Effective Oct. 1, a person's first monthly SSI payment will be prorated from the date of application or the date of eligibility, whichever is later. The payment also will be prorated for the month a person becomes eligible again after a period of ineligibility. Under the old law, a person's SSI payment started with the first day of the month in which he or she applied and met the eligibility requirements.

Medicaid coverage of home care for disabled children: In some cases, people may be eligible for SSI and Medicaid while they are institutionalized but be ineligible when living at home. Consequently, some people remain institutionalized in order to retain Medicaid eligibility, even though their medical needs could be met appropriately and more cheaply at home. Under the new law, at states' options, persons 18 or younger who otherwise would be ineligible for SSI and Medicaid if they live at home may retain Medicaid eligibility while receiving home care at less cost to the government. The change is effective Oct. 1.

Exclusion of burial plots and funds: Generally, burial plots (or spaces) for a person and his or her immediate family will no longer count as resources in determining the person's eligibility for SSI. Under the new law, however, limits may be set on the value or size of such burial plots. Burial funds for an individual and his or her spouse also will not count if they are specifically set aside for burial purposes and do not exceed \$1,500 per person, subject to certain conditions. These changes take effect Nov. 1.

Rounding of SSI payments and income limits: Beginning with the July 1983 cost-of-living adjustment, monthly SSI payments will be rounded to the next lower dollar. Also, the amount of income a person or couple can have and still be eligible for SSI will be rounded to the next lower dollar. Payments and income limits will be rounded down after they are adjusted to reflect the cost-of-living increase. Under present law, SSI payments of more than one dollar are not rounded and SSI income limits are rounded to the next higher 10 cents.

Coordination with Social Security cost-of-living increases. Under present law, the amount of a person's SSI payment is usually based on the actual income he or she had during the previous two months. Because of this retrospective accounting procedure, annual cost-of-living adjustments in Social Security benefits do not affect SSI payments until two months later. The new law continues retrospective accounting, but provides that when a cost-of-living increase is made, a person's SSI payment will be based on the Social Security benefit received in the same month. The provision will be effective with the cost-of-living adjustment for 1983.

Did you know that...?

The Milwaukee Citizen is a newspaper by and for retarded people?

And that SUNY at Brockport has developed a course called "Basic Skills for Independent Living" as one of its regular continuing education offerings? It is for adults who are retarded and need to develop the ability to get along in the community and on the job.

That disabled adults and children in Berkeley, California are educating teachers and their students about what it is like to be disabled?

That a consumer group in Princeton,

Community residences

ARCs rate high on care

A state commission has concluded that state-run community residences for the retarded in New York City provide inferior care and are 50 percent more expensive than those run by voluntary agencies.

Clarence Sundram, chairman of the commission, said that state facilities suffered from the rapid change from a 100-year-old system of putting the retarded in institutions to a system of moving patients out into smaller homes under the pressure of a 1975 court order.

"The state is not inherently incapable of running a good home," he said, "but they had to overcome 100 years of history with a gun at their heads. You take shortcuts and you can't build the philosophy of community residences under those conditions."

According to the two-year study, which focused on 14 voluntary and 10 state group homes in the city, the median cost of caring for residents in state-operated homes was \$43,093 per resident annually compared with a median cost of \$27,876 annually in those run by voluntary agencies. Even though the state facilities generally served more disabled residents and had more staff, the report said, they often provided fewer services for the money spent.

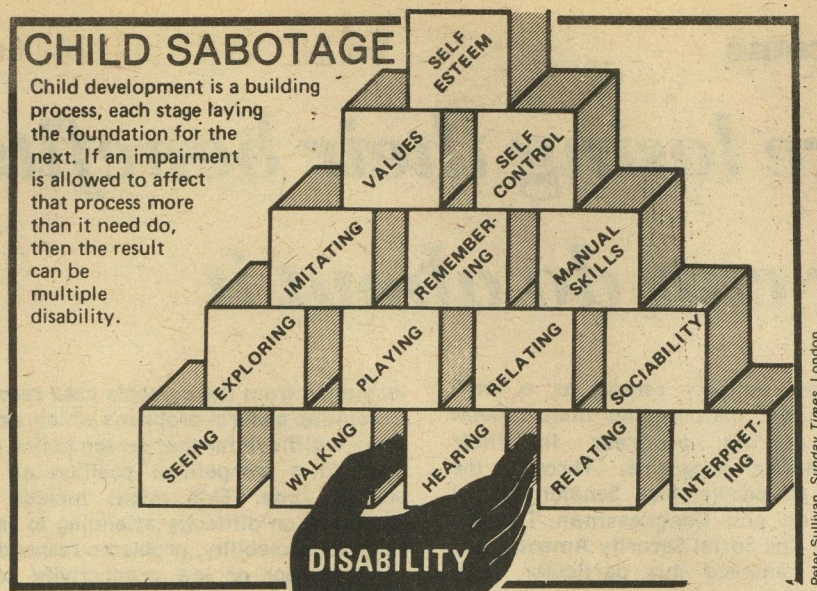
The 100-page study by the state's Commission on the Quality of Care for the Mentally Disabled also said that the placing of some groups of two or three severely retarded persons in apartments, as ordered by the court, rather than in houses was "misguided" and ought to be discontinued.

Besides costing as much on the average as the care provided in the large state facilities that the court sought to outlaw, the apartments studied by the commission had "less adequate" treatment than the homes housing as many as 10 to 15 retarded persons.

But over all, the report said, the move to community residences had been successful in cutting costs and providing "homelike and normalizing" care. The median cost for group residences, both the state's and those of the voluntary agencies, was \$28,639 a year for each resident compared with \$37,024 a year in

New Jersey has turned budget cuts into training opportunities for its clients? It is encouraging industry to do the training rather than training institutions which are getting their funds reduced.

Industry wants to help but they have to be shown how to do it is the philosophy behind the Association for the Advancement of the Mentally Handicapped. Companies like General Foods, IBM, Johnson and Johnson were encouraged to start on the job training programs and eventually hired seven mentally retarded people whom they had trained. . .



Peter Sullivan, Sunday Times, London

Congrats Oxford

The editorial reprinted below from the "Norwich Evening Sun" of June 14 pertains to local reaction to a community residence developed by Broome Developmental Center. Staff from the center held public information forums which included the participation of the village's mayor and board of trustees in order to explain the proposal. The following — in part — reflects that public education effort.

Something magic occurred in the Village of Oxford in June at a public informational meeting on a proposed community residence for the retarded in that area. It was the kind of event that helps one to draw strength from some of the basic good and kindness human beings are occasionally apt to show.

The issue of whether the community should allow a group home for developmentally disabled or retarded citizens to be located in the village had already been decided. But neighborhood residents turned out to again endorse the plan almost unanimously at a public informational meeting.

Arguments of damage to property values, concern for public safety, social and moral impact and effect on young children were tossed out the window by the village entourage. It was a powerful sign that old fears and prejudices are starting to fall by the roadside.

Group homes for the retarded are becoming more and more commonplace in communities because people are beginning to understand that being retarded is not a communicable disease or something to be frightened of but simply the fate that befalls some of our own citizens and families. We recognize that some may have concerns and fears about the impact such homes may have on their lives. But experience dictates that such programs are well-managed and sorely needed.

Helping to make a retarded or disabled individual a functioning human being is not only important but it makes good common, human and economic sense. The taxpayers and the business community both benefit when another human being becomes employable and self-supporting. Oxford residents have testified to the value, such as good neighbors. Some even think it adds an important aspect to the community. All feel that helping a human being to live in the community rather than an institution is a noble, common sense and cost-efficient goal.

The retarded display a certain level of human innocence that is more charming than frightening. They are like young children who never grow up. They can be both fragile and adventurous. Few who know or live with such a citizen fears him or her.

Some see the birth of a retarded child as a tragedy. Many parents institutionalize the child and never quite recover from the disappointment. Others have seen the event as a blessing with the child eventually teaching them what being human is all about. We are sure most parents of retarded children are grateful for the efforts made by programs such as Broome Developmental to teach their offspring independence and the ability to function at some level in the real world.

Change, such as the one that neighbors of the proposed group home in Oxford will go through, is not always pleasant but it uniquely develops a person through growth and adjustment. More important, the democratic process has clearly indicated most residents support the project. It is not being forced down anyone's throat.

We couldn't agree more with the statement of one neighbor of the proposed Albany Street residence when he indicated that the neighborhood was already unique and would have something added to it by the presence of the home. As the residents of the village attest, they probably couldn't ask for better neighbors.

the institutions, which are called developmental centers.

Mr. Sundram said that despite the lower salaries in the voluntary agencies, their direct-care employees tended to be better educated and were working in those positions in order to get experience for future employment in clinical or professional jobs.

WILLOWBROOK INFLUENCE

To many, such as Jack Gorelick, associate executive director of the voluntary Association for the Help of the Mentally Retarded, which was among the groups that brought the Willowbrook suit, the study represented stronger evidence that the state should not only continue to move patients into smaller homes but also depend more on the voluntary agencies.

"We have a running start in an area that the state has resisted," said Mr. Gorelick. "The state should be the provider of last resort for this service and that would allow them to do the monitoring that they should be doing."

Hold program line Bishops say

Catholic Bishops were urged, in a letter from Brother Joseph Moloney, Executive Director of the National Apostolate with Mentally Retarded Persons, to maintain programs and services for the mentally retarded.

At the 12th Annual Conference, Bishop John J. Snyder (Order of St. Augustine) received a special "Episcopal Leadership Award" for his outstanding work, on a national and diocesan level, toward the full participation in the life of the church of all people with disabilities.

The National Apostolate with Retarded Persons also passed the following resolution in plenary session:

WHEREAS the Pastoral Statement of United States Catholic Bishops on Handicapped People affirmed the right of all members to full participation in Church life, and

WHEREAS this right is recognized and affirmed in the National Catechetical Directory, Sharing the Light of Faith, and WHEREAS the current economic situation is having a negative impact on many areas of church ministry and diocesan programs

THEREFORE: BE IT RESOLVED that the National Apostolate with Mentally Retarded Persons encourages diocese and parishes to recognize the priority of ministry with persons with handicaps and their families and move forward in providing spiritual, educational, liturgical and social programs for them despite the current economic situation and the many other demands made on the ministerial mission of the Church.



Just loafin' and lovin' it

With Cinderella's Castle in the background, these 10 residents of the Chenango County ARC Community Residence enjoy their Autumn trip to Florida. Not only the Magic Kingdom of Disney World was visited, but also Sea World and other points of interest on their exciting vacation.

Epilepsy counts wins

Five years ago the Commission for the Control of Epilepsy and Its Consequences issued the longest, largest, most comprehensive and in every respect most authoritative review of epilepsy in the United States that had ever been compiled. It was in four volumes — but one volume was so large that it had to be divided in two, and the total number of pages was in the thousands.

When the report was issued, and presented to then Vice President Mondale and to the Congress of the United States, the overwhelming feeling of all who had worked to produce it was that it should not go the way of so many Washington reports and end its days gathering dust on a imitation teakwood shelf.

And it hasn't. A great many of those 416 recommendations that were made five years ago have actually come about — some through government action, some through the effort of EFA and its special implementation task force.

OUTSTANDING ACCOMPLISHMENTS

Let's look at some of the landmark ones: valproic acid is now available for use in the treatment of epilepsy; another comprehensive epilepsy program has been funded; a consensus conference on febrile seizures had been held; many of the research projects recommended by the Commission have either been completed or are under way; the Department of Defense has modified its rules on admission of armed services volunteers with a history of epilepsy; a large project is underway to make school personnel more responsive to children with epilepsy and to identify learning disabilities associated with epilepsy in children.

The Foundation has closely followed Commission recommendations in the structure of its public information and education programs (first, a focus on prevention, then a campaign to help the public recognize some of the subtle signs of epilepsy in a child, followed by positive presentations featuring people who have epilepsy).

The American Red Cross is changing its first aid recommendations, as the Commission suggested; camps and other recreation facilities have access to new information to help them deal appropriately

with children who have epilepsy; new drug development programs at the national Institute of Neurological and Communicative Disorders and Stroke promise better treatment options in the future; several states have produced state plans for epilepsy modeled on the Commission's recommendations; and in Puerto Rico the whole epilepsy care delivery system is based on the Commission's proposed network concept.

It was a Commission recommendation that epilepsy be decared an under-served disability for the purposes of rehabilitation, and this has now been done; the recommended guidelines for patient education will roll off EFA's presses sometime this fall; the seizure recognition film recommended for professional education is being shown regularly; and the National Information Center on Epilepsy has been established as the National Epilepsy Library and Resource Center under the sponsorship of EFA.

But the Commission's influence has been greater than the sum of its successful recommendations. The Commission's work both during its deliberations and after publication of its report had the effect of raising awareness of epilepsy throughout the health care and social service establishment. It was both a forum for explaining the need, and a catalyst to produce the changes required. Its unmet recommendations will continue to provide the spur and the rationale for future change.

The epilepsy movement owes a debt to the men and women who served on the Commission for the Control of Epilepsy and Its Consequences, a debt that can best be repaid through continued efforts to bring about the vision of a better life for people with epilepsy that was so central to the Commission's report.

And EFA itself has changed as a result of the Commission — when the report was issued five years ago there was still more than one organization for epilepsy claiming national status. The Commission recommended merger, and a year later the National Epilepsy League and the Epilepsy Foundation of America did indeed merge to become a single national organization.

(National Spokesman)

The what and why of Independent Habilitation

In a letter to the State Association, William Combes, Program Coordinator for the Protection and Advocacy Bureau, N.Y.S. Commission on Quality of Care speaks out on the importance of consumer input.

Services for the mentally retarded have greatly expanded over the years due largely to legislation such as the Developmental Disabilities Act and the Education for all Handicapped Children's Act. Implicit in this legislation is the strong mandate to habilitate the developmentally disabled individual and to follow an individualized plan for that habilitation, Combes wrote.

The plan, contract, blueprint or whatever metaphor you wish to choose, has been called the independent Habilitation Plan. It is the adult equivalent of the I.E.P. or Individualized Education Plan, which is required in all special education programs, and the concept remains constant; the plan evolves from an interdisciplinary team that includes the parent and client, and it sets goals to be accomplished in training with detailed methods for reaching these goals.

Parents, clients and advocates are now considered an integral part of the care planning process. I.H.P.'s must be completed in residential living settings as well as in Sheltered Workshops and Day Treatment Centers. The door has been opened for consumer input and the opportunity should not be avoided.

"How does the system work and why should I bother?"

I would like to briefly review the mechanics of the I.H.P. process and then address the important question of why should one bother to participate in the plan.

Let us take the example of a person entering a residential setting i.e.: group home, intermediate care facility or developmental center. The first month of that person's admission to the facility is spent in evaluation. Such areas as medical, psychological, rehabilitation, recreation, nutrition, etc. are all reviewed by an appropriate professional. These professionals submit their reports and an initial meeting is called with all professions, the parent or correspondent and the client, where appropriate.

The first meeting is the primary stage of a quarterly process that will "map out" the care of the developmentally disabled individual. It is at this point that an inventory of the client's needs as well as assets is developed. The emphasis should be on working with the client's strong points to help him or her to master the goals that the team has identified. It should not be a "laundry list" of client faults.

From the collected data, the team determines long range objectives. These are measurable statements of expected outcomes which are to take place by a certain date. The date of accomplishment is usually a year from the starting date and the objective is one that can be readily observed as completed. For example: "Michael will dress himself without assistance" is much more readily measurable than "Michael will increase his dressing skills." If Michael puts on all his clothes without anyone directing him, You know he has accomplished his task.

The long range objective is broken down into steps which will lead to accomplishment. These "steps" or "stages" are called short range objectives. Each step has a date of accomplishment and when reached, the individual moves to the next step or objective. When all short term objectives have been completed, the long range objective has been accomplished. For example: in Michael's case you might divide the task into first having someone open the bureau drawers for Michael and letting him remove the articles of clothing. The next step would have Michael opening

the bureau drawers himself, upon request, and laying out the articles of clothing. Finally, unassisted and without prompting, Michael would open the drawers himself and choose the articles of clothing.

Quarterly meetings are held to review the progress on the objectives. Parental input is elicited and if it is not, then it should be given anyway. Parents should approach the meetings with a sense that they know the individual and that they can offer concrete suggestions. Parents can serve as a "check and balance" to insure that goals are real and that they are serving a purpose.

The "why bother" question, I think, is answered in the description of the process. What better way can a parent monitor the quality of care than to be part of the "team"? They can observe the process and measure the outcome. Coupled with regular visitation, this involvement will insure that the provider will be ever mindful of maintaining a consistent level of care. It can also serve as a positive reinforcement to the provider who will be receiving feedback from the parent, where it may be impossible to receive feedback from the client.

Certainly, in any system there are "caveats". Parents should attempt to be realistic in their expectations as well as providers should be open to varying possibilities. Change comes slowly and is not necessarily accelerated because there is a plan. Objectives should be written to meet the client's needs and not the auditors needs. Fixation with "paper accountability" will divert the team from its mission.

The purpose of this article was to acquaint those who are concerned about the developmentally disabled with an important "advocacy tool". Further training in the use of I.H.P. can be arranged through the Protection and Advocacy Bureau.

Not to make use of the I.H.P. is to relinquish an important "right". It is writing a "blank check" to the provider. We at the New York State Protection and Advocacy Bureau strongly recommend familiarization with and participation in the total I.H.P. process.

"Selling" a concept is sometimes much harder than "selling" a product. The I.H.P. may appear to be intangible and time consuming. However, I hope that in this brief review of the system, I have stressed how important a "tool" the I.H.P. can really be.

Sue for self esteem

There is NO SELF ESTEEM in Prison Proximity for the mentally retarded, claims Joseph T. Weingold in a protest letter to Clarence Sundram, NYS Commission on Quality of Care.

Asking NYSARC to go to court to establish the unacceptability of "same site" locations for prisons on facilities for the mentally retarded and urging the Commissioners on Quality of Care to join in the suit against the practice, Joseph T. Weingold points out there are many other options, as abandoned public schools or underutilized hospitals.

Insistence that "same site" locations are a "temporary" move to deal with the increased need for person space was decried by Weingold as "contrary to every court decision that the mentally retarded, at the very least, are entitled to be kept from harm."

The bad effects of such co-existence, Weingold wrote, negates positive perceptions of mentally retarded and develops the public's perception that the mentally retarded may be treated as less than worthy.

Weingold's letter was prompted by an editorial in "Quality of Care" proposing that the same site solution is "an idea whose time has come."

CHAPTER NEWS

.... What our Chapters are doing
for our children and adults

Our **ST. LAWRENCE** County Chapter, announced the wedding of Wilma Welcome and Dwain Brown, two ARC clients working at the sheltered workshop in Ogdensburg. The nuptials took place on August 21st at St. Mary's Cathedral. Our best wishes to Wilma and Dwain...

Our **SARATOGA** County Chapter is very proud of their new satellite program which operates in space rented from the Ballston Spa School District...

(INSERT PHOTO B)

The first Annual Wine tasting benefit was held by **MONROE** County Chapter in conjunction with their local Stereo Station WEZO. Attendance of over 400 was expected to partake in the tasting of over twenty domestic and imported wines. All proceeds are going to the chapter for its programs...

ONTARIO County Chapter has added a Soccer Program to its already popular ongoing recreation program...

The second Annual Bowl-a-Roma was held in October by our **LIVINGSTON-WYOMING** Counties Chapter. Last year 300 bowlers in various leagues and committees raised nearly \$7,000 for the chapter. Clients and staff members in the Furniture Refinishing Department at Hilltop Industries, a division of Livingston-Wyoming Chapter were treated to a luncheon by the Genesee Holiday Inn. The invitation was extended to thank the Hilltop group for a job well done on a rush order, which consisted of stripping 60 dining room chairs. Twenty-six Hilltop clients and staff enjoyed the luncheon, which was held on October 21, 1982.

According to Rebecca DiStefano, general manager of the Holiday Inn, she mentioned the possibility of a luncheon to the Hilltop clients prior to the job as an incentive to meet the unavoidably stringent deadline.

Ms. DiStefano stated that the quality of the work done was excellent, and that the price was very competitive. The most important point for the Holiday Inn, however, was that the job be completed on time...

ROCKLAND County Chapter, offered tours of its plant to the public in recognition of National "Employ the Handicapped" week. The plant known as ARC Enterprises employs almost 200 persons on a variety of packaging and assembly jobs...

The Putnam County Deputy Sheriff's Benevolent Association gave a donation of \$500 to our **PUTNAM** County Chapter in October...

ALLEGANY County Chapter, raised approximately \$5,000 in its recent fund raising raffle, that included as a main prize a new Ford Escort, donated by Family Ford of Willsville...

Silk screening production, offset printing and wooden box manufacturing were open for the public to see at our **STEUBEN** County Chapter. The open house took place during working hours so visitors could see production in progress...

Our **SENECA** County Chapter is sponsoring a bowling program for children aged 10 and older...

ROCKLAND County Chapter held its Las Vegas night on October 16th. In addition to the 20 blackjack tables, double roulette, joker seven, and big wheel, they served patrons with an assortment of sandwiches, cake and coffee...

Another fund raising event was sponsored this fall by the **ORLEANS** County Chapter. A Ride-a-bike marathon was held, offering a ten speed bike to the person sending in the most pledges. Medina, Mayor Tukey's proclamation asked for wide support of the event by everyone who could pedal a cycle. Legislator Eddy and Albion Mayor Rodden declared Sunday, September 26th to be "Ride-A-Bike for the Retarded Sunday". The net result was \$2,279 pledged on thirty riders. Good work **ORLEANS**...



SARATOGA Chapter's Alpha Industries client working on folding and drilling a package header for **TOY WORKS COMPANY**. The workshop folds and packages fabric toy kits at the Milton Avenue building. The contract involves 15 clients who fold preprinted fabric; insert kit component parts into poly bags and staple headers on bags. The contract is ongoing and had doubled in volume since it was initiated in September 1980.

Over 100 people attended the dedication of **OTSEGO** County Chapter's new plant. It was a gala event, with the chapter proudly showing off its multi-faceted production capabilities and the final results of its \$600,000 renovation project...

"Get To Know Us", was a four page review in the September 30th edition of the Chronicle-Express describing the mission and services offered by our **YATES** County Chapter. This pictorial review certainly ranks among the best in the State. Our hats off to **YATES** chapter for getting our point across so well...

Our **ERIE** County Chapter was the benefactor of a fund raising softball game played between the Buffalo Police Department and the Erie County Sheriff's Department. Over 3,200 fans viewed the game and the accompanying horsemanship exhibition. Everyone had a great time...

SCHOHARIE County Chapter celebrated the second anniversary of its apartment program. The chapter is proud of the success of this program as it offers residents that important intermediate living situation so necessary to continued self-actualization...

BROOME-TIOGA Counties Chapter held its twenty eighth Annual Dinner Dance in September. Over 200 persons attended this enjoyable event and heard Senator Warren M. Anderson say, "We have not solved all of the problems and may never really solve them all, but the spirit of the people in this room has given us, who try to allocate funds in Albany...thought." On another note **BROOME-TIOGA** employees had an excellent time at the 2nd Annual Special Olympics Softball Tournament that was held on September 11th. Over 120 people took part in the games. Three cheers for all who participated in the games and most certainly for all the volunteers who made them possible...

COLUMBIA County Chapter held its first Annual Benefit Auction and raised \$1,800. besides the many items of Americana offered by auctioneer Ed Freedman, there were guest appearances by local and national celebrities...

The Eleventh Annual Harvest Ball has been held at our **SCHENECTADY** County Chapter. The event was organized by the Elks club and ARC volunteers. Music was provided by the Music Performance Trust

Fund and Local 85 of the American Federation of Musicians. A great time was had by all...

NASSAU County Chapter will start construction on its new Day Treatment Center before the end of 1982. The facility is expected to cost about \$4.5 million. It will initially have 125 currently in a day treatment program, but will eventually serve approximately 250. Of the private funds going into the construction is \$1,000,000 was raised by the Cissy Birnbaum - Five Towns Auxiliary to honor the memory of Cissy Birnbaum...

The **RENSSELAER** County Chapter conducted a very successful Dance Marathon on October 2nd at their new Day Treatment Facility in Pittstown, New York. Over \$4,000 was raised by participants including local high school and college students. The award for most money pledged per hour went to Ellie Pattison, who was kicking off her last week as State ARC President, and Ara Baligian, Mental Health Commissioner for Rensselaer County. Together, Ellie and Ara had \$114.26 per hour pledged. With such high stakes, they managed to survive aching feet and over-worked ear drums to last the entire fifteen hours of the Marathon.

Speaking of the Rensselaer ARC Dance Marathon, the Chairman of that event, Ted Greeley, also received quite an honor this fall. Ted was recipient of the volunteer of the Year Award from the Capital District Chapter of the National Rehabilitation Association. In addition to his many hours of work in planning and running the Dance Marathon, Ted is a regular volunteer at the ARC's Day Treatment Program, where he has established an outstanding relationship with many of the trainees in the program. Ted, whose wife Lorraine is Secretary at the Day Treatment Program, manages to bring a great deal of enthusiasm to his volunteer efforts with the ARC. Both the Rensselaer Chapter and the State ARC salute Ted Greeley upon his award from the National Rehabilitation Association.

Riverside Enterprises, a Vocational Rehabilitation Program operated by the Rensselaer ARC, has received a great deal of recognition in recent months. The Matthew Bender Company, a major

Genesee and me

Awareness of the actual and potential business climate has been generated by the recent "Genesee and Me" Industrial Exposition in the Genesee Country Mall. The "Genesee and Me" campaign continuing through the Chamber and the Genesee County Industrial Development Agency, is contributing to this awareness and promoting community cooperation for the betterment of the economic climate for the residents of Genesee County.

Among those concerns receiving recognition for their contributions and part in the Genesee economic picture is the Genesee County Chapter of the New York State Association for Retarded Children Inc. (also known locally as Genco Industries).

This sheltered workshop is a non-profit facility which teaches work skills and attitudes, in a realistic production setting, to the 117 adults currently enrolled. The ARC provides employment in a productive, satisfying and tolerant setting for those who cannot meet the standards of competitive industry. In addition it also provides vocational evaluation, personal adjustment programs, transportation, residential programs, and job development and placement for its client workers.

Gross expenditures for 1981 from these endeavors will amount to over \$700,000. All but \$37,000 is generated from business operations and sources outside Genesee County with the majority returning to Genesee County businesses and services. The multiplier effect is thus in action here. The Genesee County ARC is a revenue generator plus offers the only service of its type in the county for the disabled of the Genesee community.

Volunteer elected to office

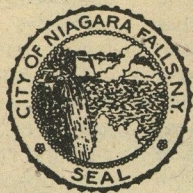


Linda Van Dusen, (Warren - Washington Chapter) receives emblem of office from Kay Williams, Installing Officer, New York Grange.

Gertrude Van Dusen snapped this picture of her daughter, Linda, at a recent ceremony of the Mohican Grange No. 1300. Linda was thrilled to be elected to the office of Flora. Linda Van Dusen is a volunteer, not only at the Grange, but in her church and at ARC when needed. The Van Dusens reside in Glens Falls, New York and are active charter members of our Warren - Washington Chapter.

contractor with Riverside Enterprises, recently featured an article in their In-House Newsletter about the Law Book Updating work being done at Riverside. In addition, the United Press International did a state-wide article on some of the high technology work being done by Riverside for companies such as Fairchild Test Systems.

CONVENTION ACTION



OFFICE OF THE MAYOR
CITY OF NIAGARA FALLS, NEW YORK

Proclamation

WHEREAS;

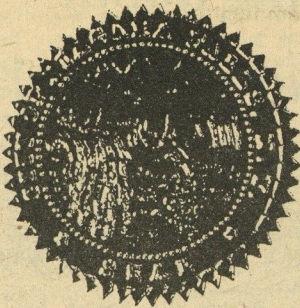
Children have always been God's chosen little ones. Perhaps that is why it is so difficult to understand why any of them should suffer mental retardation. But even in our worst moments of crisis and self-doubt, we receive an inner enlightenment which shows us that, even if we can't understand, God does have a reason;

And we know that, in our loving care and concern for others in distress, we share something of God's will, for He has deemed that love which is strong enough to help carry some of other people's burdens, will always have the last word over meaningless suffering;

And since the NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN's work stands as a sterling example of love that can be wielded to work, not in a tempest of miracles, but in a gentle, kind and quiet way, public recognition of this exemplar group becomes both an act of appreciation and a call for public involvement. By helping them in their work, we too will share in the answer Almighty God is certain to have for us;

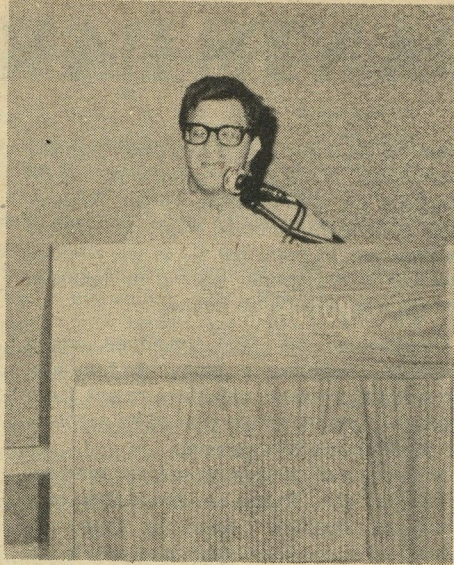
NOW, THEREFORE, I, MICHAEL C. O'LAUGHLIN, by the power vested in me as Mayor of the City of Niagara Falls, New York, do hereby proclaim Saturday, October 9, 1982,

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN'S DAY

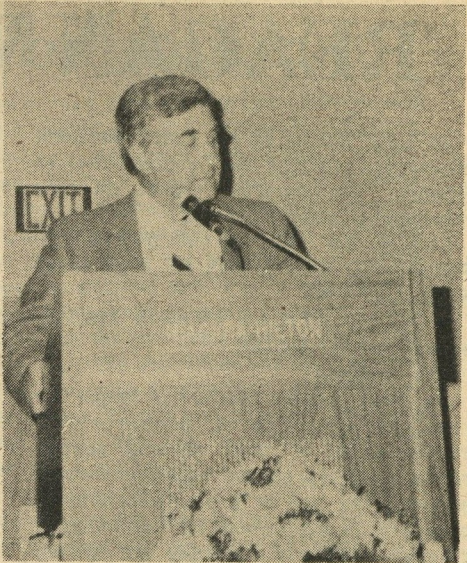


IN WITNESS, WHEREOF, I have here-
unto set my hand and caused
the Seal of the City of
Niagara Falls to be affixed
this 9th day of October, 1982.

Michael C. O'Laughlin
Mayor



Jonathan Weingold Opening Convention



Commissioner Slezak speaking at banquet



The swearing in ceremony (left to right) George Hirsch, NYSARC Treasurer, Shirley Reynolds, NYSARC Secretary, David Lettman, Senior Vice President, Richar Marcil, Central Region Vice President, Shirley Valachovic, Northeast Region Vice President.



Eleanor Pattison, President, turns the reins over to newly elected President, Irene Platt as Henry Kalfas looks on.



The Mayor of Niagara Falls, Michael O'Laughlin Proclamates Special Attention to Mental Retardation Services in his city.



Irene Platt, NYSARC President, David Lettman, Senior Vice President and George Hirsch, Treasurer.



President Irene Platt and Executive Director Marc Brandt chat with Harvey Platt during annual banquet.

REAGAN WANTS PARENTS OUT OF INPUT

Jo Scro, Editor of Advocacy Network Newsletter clarifies the Congressional vs Reagan Administration moves on new regulations under PL 94-142.

SUMMARY AND ANALYSIS OF PROPOSED REVISIONS OF P.L. 94-142 REGULATIONS

I. EVALUATIONS (NPRM 300.139-300.144, 300.157-300.159)

The Problem

Parental consent would no longer be required prior to a preplacement evaluation of a child needing special education. The proposed regulations would abandon the use of a multidisciplinary approach in evaluating all handicapped children. Similarly discarded are current requirements that test and evaluation materials must be validated, professionally selected for the specific purpose for which they are to be used in determining the services to be provided, and administered by qualified personnel.

No longer would a child have to be assessed in all areas related to the suspected disability or re-evaluated at least every three years. Finally, the burden has been shifted onto parents to justify gaining an independent evaluation at public expense. It would fall to them to initiate a hearing and convince a hearing officer of the necessity of such an evaluation.

Needed Action

The existing regulation, 300.504, requiring parental consent before a preplacement evaluation is conducted or an initial placement is made, must be retained. 300.158 of the proposed regulations should be revised to ensure that tests and evaluation materials are validated for the specific purpose for which they are used and administered by trained personnel. 300.141 of the NPRM should continue the requirement that a child's placement be re-evaluated at least every three years or if the child's parent or teacher requests such an evaluation. The current provisions governing independent evaluations should remain intact.

Rationale

The Reagan Administration's revisions inherently foster the misclassification of black and other minority children as mentally retarded and spawn serious cost inefficiencies stemming from inappropriate placements. Incomplete and inadequate programs can only be a direct result of such diminished and delayed evaluation procedures. Substantial harm to handicapped children would ensue.

II. INDIVIDUALIZED EDUCATION PROGRAM (IEP) (NPRM 300.114, 300.120-300.128)

The Problem

Deleted from the proposed regulations is the present obligation that a member of the evaluation team or someone experienced in the evaluation procedures attend the IEP meeting when a child has been evaluated for the first time.

The Administration's proposal would also eliminate the timelines which now requires that an IEP meeting be held within 30 days after a child has been found eligible for services. Under a new guideline, IEPs would not have to be actually drafted at IEP meetings; in fact, the proposed regulations permit their writing at some future, unspecified date. Finally, the IEP process is specifically circumvented to an NPRM revision which would allow educational agencies to expel handicapped children for behavior that is not caused by the child's handicapping condition and to allow routine suspensions of handicapped children.

Needed Action

300.124 of the NPRM should be revised to provide that someone knowledgeable about evaluation procedures or a member of the evaluation team attend the IEP

meeting for a child who has been initially evaluated. Existing regulations which mandate an IEP meeting within 30 days after a determination of eligibility should be retained. In turn, 300.114 of the NPRM, relating to discipline, having no basis in the statute, should be deleted.

Deletion of the IEP timelines would promote unnecessary delay, and misunderstandings would naturally result from the lack of requirement that IEPs actually be drafted at IEP meetings.

With regard to the proposed disciplinary revisions, the Reagan Administration's proposals remain flawed in that fundamental placement decisions would be made by local administrators, rather than trained special education personnel. As a result, a seriously emotionally disturbed youngster may be expelled, for example, for behavior which a local principal, and not the IEP team, determines is not generated by the underlying condition.

III. RELATED SERVICES (NPRM 300.4(b) (10))

The Problem

Educational agencies would be permitted complete discretion to define related services and adopt "reasonable limitations" as to the provision and amount of such services in any IEP. The Administration's revisions completely delete the present requirements for provision of school health services, social work services, and parent counseling and training. Related services personnel would no longer have to be certified or licensed by the state. The regulatory proposals would expand the definition of "medical services," which do not have to be provided. The proposed regs would no longer require schools to administer any medication to a handicapped child, barring some epileptic or diabetic children from attending school.

Needed Action

The existing regulations which define related services in 300.13 should be retained. Provisions allowing limitations on such services, such as NPRM 300.4 (10), should be deleted. School health services represent an especially important related service needed for some children, those with diabetes or epilepsy for example, to remain in school. It should be retained, along with the current definition of medical services contained in 300.13(b) (4).

Rationale

The overall impact of the proposed changes would be to deprive many children of services to which they are currently entitled. States could broadly and extensively restrict the availability of services, regardless of need. Also, the proposed regulations appear to prevent a child with diabetes requiring an insulin shot, or a child in need of clean intermittent catheterization from receiving such services from school personnel in order to remain in a regular educational setting, contrary to the intent of the law and a number of judicial decisions. Under some circumstances, denial of school health services could preclude individual children from attending school at all, denying them a free appropriate education.

IV. LEAST RESTRICTIVE ENVIRONMENT (NPRM 300.113, 300.160-300.161)

The Problem

The Administration's revisions would relieve school districts of present obligations to: (1) place handicapped children as close to home as possible; (2) provide placements in a local, neighborhood school, unless otherwise indicated; and (3) ensure that in organizing non-academic and extra-curricular activities, handicapped children participate with non-handicapped peers to the

maximum extent appropriate.

No longer would school districts have to provide a continuum of alternative placements and supplementary services in order to implement an IEP. Similarly deleted are existing provisions ensuring the availability of programs and services to handicapped children comparable to those offered non-handicapped children. Finally, the proposed regulations would permit school officials to weigh the "disruptive" impact upon non-handicapped children of a placement of a handicapped child in a regular educational setting.

Needed Action

The existing regulations 300.550-300.556 should be retained, including the requirement that state educational agencies monitor the compliance of local school districts in this area. Current provisions which ensure the availability of a range of placements and services reflect a central component of P.L. 94-142 and do not warrant elimination.

The Administration's changes would result in reduced placement options, a significant retreat from the commitment to educate handicapped children with their non-handicapped peers, and support for more expensive, isolated placements for these children, including institutional placements. Fostering such a direction would violate the Congressional intent in enacting P.L. 94-142, as well as work against the best interests of handicapped children. The revisions would indeed encourage the segregation of handicapped children into special classes and institutions by allowing some school officials to use the rationale that mainstreaming would have a "disruptive" impact on the education of non-handicapped children.

V. PARENTAL RIGHTS AND INVOLVEMENT (NPRM 300.125, 300.145-300.152)

The Problem

In addition to the deletion of parental consent to a pre-placement evaluation, parental consent would no longer be required before a child is initially placed in a special education program. Educational agencies would not be required to notify parents of the evaluation results relied upon in making decisions as to a child's program and of other options considered.

The Administration's proposals eliminate current provisions obligating school officials to document notice efforts to promote parental participation and also embrace reduced requirements to ensure that parents fully comprehend what happens at an IEP meeting. Alternative methods of parental participation, such as the use of conference calls, are eliminated. Documentation requirements are also deleted.

The proposed regulations similarly restrict parental rights in the hearing process. No longer would parents be entitled to receive information about advocacy services, to exclude "surprise" testimony (by being informed of all evidence at least 5 days before the hearing date), or to open the hearing to the public. In addition, expanded timelines for hearings and administrative appeals would afford educational bureaucracies increased opportunities for delay.

Needed Action

Existing regulations ensuring parental involvement and rights must be retained, including those governing consent, IEPs, evaluations, and due process hearings.

Rationale

Permeating the recent U.S. Supreme Court decision on P.L. 94-142, *Hendrick Hudson District Board of Education v. Rowley*, was the Court's determination that the procedural safeguards afforded to parents of handicapped children were necessary to assure the provision of a free,

appropriate education. The Court specifically emphasized and upheld the extensive procedural requirements affecting parents.

The Administration's revision would directly undercut these requirements and foster a less informed, less involved parental role in the education of children with special needs. Indeed, under the NPRM and IEP meeting for a child may be held even though the local school district has never even directly contacted the parents. A few unanswered phone calls, while the parent is away at work, may well be used to satisfy the standard of "reasonable attempts" to reach parents before school officials proceed without them.

Conclusion

The collective impact of all these revisions should not be underestimated. Under these new provisions, many of the most important features involved in the education of handicapped children have been assailed: parental involvement would be limited, services be restricted, procedural protections diminished, and less restrictive placement become more a matter of discretion than right. There is no justification for these proposed changes. The public should ask Congress for a swift legislative veto, and the Department of Education should retain and enforce the current regulations.

Is administration lying about Social Security?

Social Security statements as reported in handouts to the press contain ridiculous, untrue statements claims John S. Hogg of Hamilton, N.Y. in a letter to the *Watertown Times*.

Mr. Hogg chided the *Times* for its reporting.

"August 29, 1982, you published two articles, under the headline 'Social Security closing door on disabled?' In one of the articles you mentioned one unfortunate case, and indicated some dissatisfaction in Congress. However, neither article contained any factual or statistical information except self-serving handouts from the administration — particularly, repeated three times as if it were true, the statement that 97 percent of the cutoff decisions are correct.

The claim of 97 percent accuracy (Completely absurd for any government program) is a conscious and deliberate lie. When an official of the Social Security Administration testifying before a congressional committee was asked why, with this amazing degree of accuracy, two-thirds of the decisions were reversed by the administrative law judges and the courts, the official blandly replied that the judges were wrong!

The fact is that the large number of cutoffs results specifically and directly from administrative policies which have been knowingly and intentionally designed to violate the Social Security Act, with all of its amendments, as passed by Congress and interpreted by the Courts, and the duly issued regulations of the Social Security Agency itself.

It is the deliberate lawlessness of the Social Security Administration that leads to the very high percentage of reversals of these decisions which the claimants are physically and mentally able to fight."

NEWS AND VIEWS of the EDUCATION COMMITTEE

BETTY PENDLER, CHAIRPERSON

Education Committee points with pride to our participation in the recent public hearings on the proposed regulations for PL 94-142. Marilyn Wessels was practically first in line to testify in Washington, D.C. and made the press with both UP and AP. Judy Shalvey, another member of the Education Committee, spoke forcefully in New York City and made the Daily News - so not only did the concerns of parents get heard - but NYSARC received due publicity.

SAVE THE DATE...MARCH 25, 1983

Our annual spring workshop will be held at the Sheraton Hotel in Syracuse this year. This workshop is being coordinated by Education Committee member, Thomas Scholl, and the theme will be on parent-professional cooperation among other things, and how we can effect changes. We hope that all chapters in that area will help in publicizing this workshop, so that school districts, members of committees on the handicapped, other organizations in the area, and professionals and parents will want to attend. Full particulars will be forthcoming. We hope that chapters will see the need for parents to attend such meetings, and if necessary set up a fund to subsidize a few of them to enable them to attend.

When the program and registration forms are mailed out to you, we hope that every chapter will notify membership either by doing a separate mailing or including the information in their newsletters. The workshop is geared for all persons on all levels -- new parents, parents helping other parents -- staff who will be working with parents and educators, legislators and other professionals, so we look forward to an exciting day on MARCH 25, 1983.

LEGISLATION NEW FOCUS FOR PARENTS

It is going to be very important to get to know our legislators; our state assemblyman, our state senators, and our United States Congressman and United States Senators because it has already been proven that once they know what we are concerned about they can make a difference.

In the recent proposed changes in the regulations which seriously affect the implementation of PL 94-142, most of us wrote to many legislators, and they all responded, and it was the barrage of mail they received that, temporarily at least, postponed the passage of the regulations. We cannot let up on our vigilance. We must all be aware of the proposed legislation. We must all watch out for notices of public hearings, and we must contact our representatives. The NYSARC through its Legal and Legislative Committee will keep you informed, but we urge you to write and telephone - and write again and again. Legislators tell us that they are disappointed that they do not hear from their constituents enough - so let's keep them busy.

IMPACT REPORT

We received a letter from U.S. Commissioner of Education, Terrel H. Bell, in which he announces the withdrawal of the six major areas that were originally listed in the Federal Register of August 4. They are (1) Issues of parental consent prior to initial evaluation or initial placement in special education, (2) Least restrictive environment, (4) Timeliness, (5) Attendance of evaluation personnel at IEP meetings and (6) The qualifications of personnel. However, that does not mean that new wordings might not be slipped through in the future. His office also states that in a forthcoming issue of the Federal Register (NPRM-Notice of Proposed Rulemaking) his department will cover the entire regulation, which will be subject to another public comment period. We all must be alert to such changes in early 1983.



'Exceptional person' Pender receives award for service

In accepting this well-deserved award, Betty Pender - NYS ARC Educational Committee Chairperson, expressed her appreciation for recognition of her efforts in special education particularly to bridge the gap between parent and professionals. "I owe most of my inspiration for working so hard in this field to my participation in and the activities of the New York State Association for Retarded Children." Betty added "If it were not for my daughter, Lisa, who is mentally retarded, I never

would have had the opportunity to experience the rewards and joy of meeting and working with the many wonderful professionals in CEC (and the other two professional organizations here tonight) American Association on Mental Deficiency and New York State Teachers of the Mentally Handicapped who have shown me that they, indeed, share the concerns of the parents, and are anxious to work together for our mutual benefit."

SECTION 504...PROPOSED REGULATORY CHANGES

As if we do not have enough headaches with PL 94-142, we have been informed that new guidelines governing the implementation of Section 504 of the Rehabilitation Act of 1973 are currently under review of the Office of Management and Budget.

It is important for us to realize that Section 504 has implications for all individuals, beyond the school-aged populations, so that every committee should be alerted to these changes.

In the area of education however, PL 94-142 and Section 504 reinforce each other. If Section 504 were not enforced through strong regulations, a state or local school district could avoid its obligation to provide a free appropriate public education to children with handicapping conditions by turning down the limited funds that are currently available under 94-142. Up until now, we have been complacent in feeling that even if changes were made in regulations for PL 94-142 we still had Section 504 to fall back on. But the danger is that we may get a watered down version.

Section 504 is virtually the only law that requires society to provide equal access to health care, dental care, vocational training, jobs and recreation to those over the age of 18. These regulations, too, will be published in the Federal Register, allowing for a period of public comment.

We urge you to be in touch with the Department of Justice, Civil Rights Division, Coordination and Review Section, located at 10th and Pennsylvania Avenue, Washington, DC 20530. (Whoever said it was easy to be a parent of a child who is handicapped?)

EDULETTER

We will continue to publish this three times a year with all the latest information available, but we are extremely anxious to make this a CHAPTER letter, rather than just a Committee publication. We therefore continue to urge you to send us information on what chapter is doing in educational advocacy, the kind of problems your parents are experiencing or other successful techniques you parents have developed to deal with the bureaucracy. If you are not on our mailing list to receive this informative publication please fill out coupon on the end of this column. If you are, and want your school officials to receive this, pass on the coupon to them.

CHAPTER NEWS EDITORS ALERT

chapter news editors 8 alerts

How about reprinting this coupon in your own letter for those parents who still might not have heard of us?

NEW MEMBERS FOR YOUR CHAPTER

Do you realize that if you could reach out to parents whose children are in nursery school, day centers or head start programs and begin to prepare them to deal with committees on the handicapped etc., they would be happy to join your chapter? Your chapter is prepared to give a very real service to parents - why not reach out to them?

EXCEPTIONAL PARENT MAGAZINE, Boylston Street, Boston, Mass 02116, still continues to be a leading publication in our field for parents and professionals. It is well-worth the \$15.00 yearly subscription. The Education Committee recommends it highly.

REPRINTS...The Education Committee now has 54 reprints of articles which could be very useful for any chapter having membership meetings on the subject of the public school, parent teacher relationship etc. They are valuable tools for any workshop you may be planning, and remember, our committee will be delighted to cooperate in this endeavor. Send to the state office for latest listing. They're great for fill-ins for your newsletters where we hope you have an Education Column.

We know that many of our chapters have great talents doing great things. Please let us hear from you, and share the wealth. If any of your members of your chapter Education Committee, or staff working with parents, run into any special problems, we would like to hear about it.

The following are members of the Education Committee of the New York State Association for Retarded Children. Please feel free to contact any member of the Committee if you have any specific concerns or wish additional information.

Calkins, Janet; R.F.D. 3, Box 248 Plattsburgh, NY 12901. Phone 518-643-8889.
Flala, Joan; 19 Exeter Drive, Endicott, NY 13760. Phone 607-754-7307.

Goodman, Thomas; Box 812 South Fallsburg, NY 12779. Phone 914-434-3415.

Murphy, Mary; 41 Dirksen Avenue West Seneca, NY 14224. Phone 716-826-6344.

Reynolds, Shirley; 864 Colvin Blvd. Kenmore, NY 14217. Phone 716-876-0577.

Scholl, Thomas; 7828 Moon Valley Drive, Liverpool, NY 13088. Phone 315-457-3750.

Shalvey, Judy; PO Box 961 Miller Place, NY 11764. Phone 516-473-0430.

Sullivan, Georgia; 11 City Terrace North, Newburgh, NY 12550. Phone 914-338-5322.

Pender, Betty; 267 West 70th Street New York, NY 10023. Phone 212-873-6094.

Wessels, Marilyn; 160 Clayton Road, Schenectady, NY 12304. Phone 518-474-4665.

I wish to receive the Newsletter of the Education Committee of the NY State Association for Retarded Children.

NAME.....

ADDRESS.....

TEL. NO.....

CHAPTER AFFILIATION

(A) This is a new request. Please add my name to your mailing list.

(B) I wish to continue receiving Eduletter.

Return to:

Betty Pender, Chairperson

Education Committee

N.Y. State Association for

Retarded Children, Inc.

1175 Fifth Avenue, NY NY 10010

Conference Scheduled

Patricia Burns, Conference Chairperson for the Council for Exceptional Children Geneseo, New York reports the theme for this year's conference is "Current Trends in Special Education." The conference slated for March 4th and 5th will cover such topics as Current Legislation, Computers and Special Education, Behavioral Technology, Group Homes and many others.

For more details contact Patricia Burns, Box 54, College Union, SUNY at Geneseo, New York 14454.

Westchester heads Advocacy Network

By Betty Pendler

A PARENTS EDUCATION NETWORK (PEN) was the focus of Westchester Chapter's first Parent Advocacy Training Seminar in October at the WARC Katzenberg Training Center. Betty Pendler, Chairperson to NYSARC's Education Committee attended and commented that "this chapter is following what the Education Committee has urged since its beginning - helping the new parent who is going to the Committee on the Handicapped for the first time."

WESTCHESTER EDUCATION COMMITTEE ACTION

Barbara Levitz and Liz Villani, co-chairpersons of the Education Committee, from Westchester Chapter, know full well how important it is for parents to know the law, to learn how to be assertive and speak up for their rights, to know the right questions to ask when they go to a committee on the handicapped, to be able to help a new parent who is going to the Committee on the Handicapped for the first time, to know where to send for information, etc. That is why they have just established a **PARENTS EDUCATION NETWORK, TO GIVE NAY CHAPTER THE BENEFIT OF THIS RICH AND EXCITING EXPERIENCE.** Westchester Chapter will supply a copy of the program to indicate how easy it can be done. The quality of the speakers, and the wealth of resource material presented was enough to inspire even the most timid parent present. The committee has drawn much of their inspiration from Mary Kallet, Assistant Executive Director of WARC, who has not only been a long standing champion of the State ARC Education Committee, but has worked equally enthusiastically in her own chapter. (She is indeed fortunate to have such a terrific committee.)

The keynote address was given by Clarence Sundram, Chairman of the N.Y. State Commission on Quality of Care. Other outstanding outside speakers were Kay Franks, Westchester Student Advocacy Coalition, who spoke on the role of the Advocate in Working with Students, Family and School, Helga Bendix, well known parent advocate in the Westchester area, spoke on the Educational Rights of Children with Handicapping Conditions.

During a brown-bag luncheon, Marilyn Wessels of NYSARC Education Committee gave a talk on "The Need to Change Community and Professional Attitudes Toward the Handicapped."

The training session was modeled very much after some of the workshops given by the Commission on Quality of Care; i.e., presenting hypothetical advocacy case studies, led by Deborah Michelle Sanders, lawyer, which was done in role play and discussion.

Michele Winograd, President of Westchester Association for Children with Learning Disabilities, gave an excellent presentation on the Advocacy Process in which she urged parents to learn to be assertive, - watch out for "cool-outs", always to sit where you have eye-contact with the school officials. She suggested a new technique if you need a little time to compose yourself at a hearing -- feign a coughing spell, so you have to go out and get a drink of water (during which you can control your anger and-or thoughts), or accidentally spill some water, so that during the time of the cleanup, you can collect yourself.)

Dr. Brian Hurvitz, Professor of Special Education of Lehman College, and a member of the Westchester Education Committee gave an extremely informative talk on understanding Evaluations. He has given the NYSARC Education Committee permission to reprint these in their upcoming Edeletters.

Final presentation was a review of available resources that parents may send for, given by representatives of advocacy organizations in Westchester. The parents learned it isn't so difficult to get to know your rights. There are lots of people out there ready to help parents and much printed material is available (including now the Commission's advocacy kits), and despite the crisis we are all going through in public education, a parent who knows his rights and speaks up, and GETS INVOLVED has a chance of succeeding.

It is hoped other chapters will replicate this PEN process. This is the time, more than ever before in the history of public education, that it is vital parents know what is going on.

Kansas, Ohio lead motor advance

The states of Kansas and Ohio have recently established innovative programs which focus on improving muscle and motor development for retarded children and adults. In Kansas, the Oral Muscular Therapy Program was initiated to maximize the function of the oral musculature (tongue, lips, jaw and soft palate) to obtain a maximum level of eating and drinking independence. Meanwhile, the Ottawa County (Ohio) Board of Mental Retardation has set up the Perceptual Motor Development Clinic to develop muscular strength, endurance and neuro-muscular coordination through the use of Kinesiotherapy exercises and motor activities introduced in a play environment.

The Institute of Logopedics in Wichita, Kansas introduced the Oral Muscular Therapy (OMT) program for disabled children in August, 1979. OMT is designed to improve oral muscular skills essential to optimum eating, drinking, and articulation so that a handicapped child may realize his/her potential for vegetative, as well as, communicative functioning. Additionally, disabled children are provided with adaptive equipment and self-feeding techniques to promote independent, socially acceptable mealtime behaviors through the OMT program.

After a child has been recommended for an oral muscular evaluation, permission for evaluation and treatment, if wanted, is obtained from the child's attending physician and parents. A child is seen on a daily basis during the noon meal by a professional or paraprofessional trained in OMT.

Following a treatment plan designed by coordinators of the OMT program, the therapist applies oral muscular modification techniques before and during the meal in addition to techniques designed to improve self-help skills. Parents, houseparents, and professionals on the child's management team are trained in applying new management techniques to ensure carryover to additional settings. The child is withdrawn from the daily program after oral muscular skills have developed maximally during treatment sessions. Afterwards, the child is monitored at his/her residence or in the school cafeteria on a weekly basis for one month, after which time the program is terminated if new skills have stabilized. A re-evaluation is completed every four months until no further treatment is indicated.

Request for additional information should be directed to: Connie Pickler, Oral Muscular Therapy Program, Institute of Logopedics, 2400 Jardine Drive, Wichita, KS 67219.

(— New Directions, August)



Stella Sheib responds with thanks, in the presence of Agency representatives, officials, family and friends.

Sheib dedication at Westchester

The Yonkers Training Center of the Westchester Association for Retarded Citizens was dedicated recently as the Simon Sheib Training Center, in memory of the man who made a major contribution to the building and its services. The ceremony marked completion of the expansion of the building at 567 Yonkers Avenue which added 5,000 square feet of space to serve the 175 mentally disabled adults who attend its day programs.

Participating in the dedication ceremony were Yonkers Mayor Angelo Martinelli, State Senator John Flynn, WARC President Ann McDonnell, Dr. Eugene Aronowitz, Commissioner of the Westchester County Department of Community Mental Health and Mrs. Simon Sheib of Larchmont and her family. Preceding the ribbon cutting, invited guests toured the facility in small groups, viewing programs in operation.

The expansion marks the first major renovation of the building since the agency moved the Yonkers program there in 1974. A major capital fund drive over the past

several years was mounted to cover the cost of expanding the building's upper floor and roofing over the new addition. The extra space provided has been urgently needed to accommodate increased services to agency clients.

Mr. Sheib, who died in June 1980, was largely responsible for the continued growth of WARC over the past 30 years. Together with his wife, Stella, he provided funds and guidance that enabled the agency to establish pre-school programs and services to an ever increasing number of adults and their families. He was a former Board member of the agency and at the time of his death was Chairman of the Board of the Avnet Corporation in New York City. The firm generously contributed to the expansion of this building upon Mr. Sheib's death. He was an avid golfer, and organized a pro-amateur mini classes (which became an annual event,) to benefit WARC.

Dr. Herbert Pinsley of Scarsdale, a WARC board member, and his wife Deane planned and directed the event.



Training Center clients hold ribbon for Mrs. Sheib to cut.

Talent not disabled, only people are

By Kate Klein

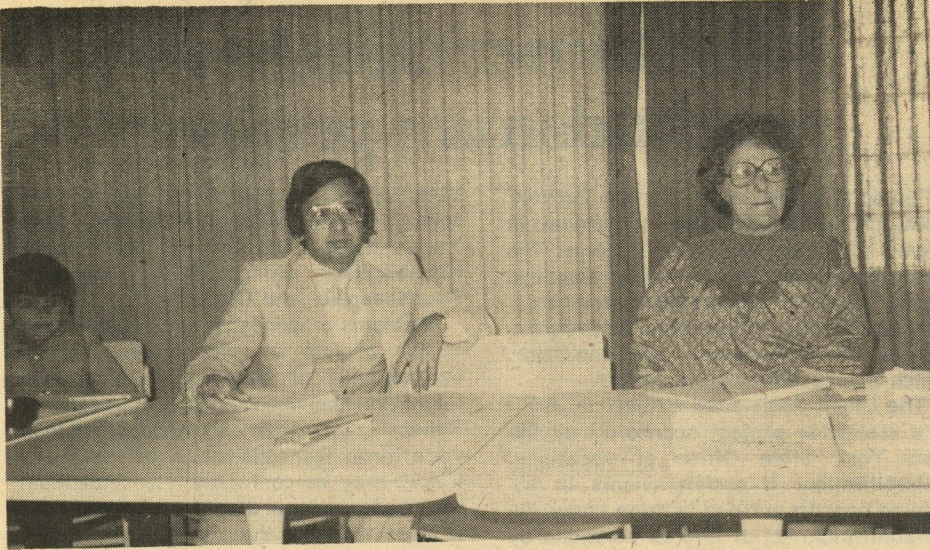
Although people who are mentally retarded are not in National Theater Workshop for the Handicapped, Brother Curry explained, look at the outstanding performance given by the total cast of mentally retarded people in the International Year of the Disabled promotion "The Mikado". This was produced successfully by people in a residence in Australia and has been shown on Public television all over America.

"We are insinuating our presence in the media world", Brother Curry told reporter Kate Klein. Madison Avenue (the prototype of successful media advertising) does not "do disabled" he commented. Somehow the fact that the disabled eat, buy clothes, enjoy the arts and are talented has not struck them yet. We are proving through our theater workshop that talent is not limited to those who are able.

National Theater Workshop for the Handicapped is located for correspondence purposes at 106 West 56th Street, New York, N.Y. 10019.

A current goal is to see one of our actors in a national television commercial. Right now the advertising media cannot equate the enjoyment of food or other products with the disabled performer and consumer. That is their hang up, not ours, he concluded.

Focus of NTWH workshop training is what any theater workshop has as its goal — professional output. Jesuit Brother Rick Curry, trained in the Stanislavsky Method himself claims for too long the disabled have had to accept the "able view" of themselves. "But our purpose is quality performance. As actors, we have the same talent, accompanied by the same insecurities, first night jitters as any professionals who are not disabled."



Keynoter Clarence J. Sundram and Elizabeth Villani.



Left to right: Barbara Levitz, Marilyn Wessels, Helga Bendix.

Networking the advocacy way

Persuaded by NYSARC's Education Committee, the NYS Commission on Quality of Care For the Mentally Retarded took on a pilot project recently in which 14 chapters participated.

The project purpose was to train and establish a growing network of trainers for parent advocacy in school-committee in the handicapped situations.

Rapport established during on site visits to chapters to provide technical assistance greatly aided advocacy attitudes. Commission staff met weekly with Marilyn Wessels (NYSARC Education Committee) to plan and implement the give and take of chapter commission training materials.

Chapters taking part in the project were: Albany, Columbia, Delaware, Fulton, Greene, Montgomery, Oswego, Rensselaer, Saratoga, Schenectady, Schoharie, Warren-Washington, O.C. Heck and Wilton Developmental Centers.

NYSARC's Education Committee chairperson, Betty Pendler, praised the network training session. "This project spells out the 'raison d'être' of our committee, which is, through individual chapter efforts, to assist parents to advocate for their child."

COMMENTS FROM CHAPTERS MEMBERS

Saratoga ARC — "I have been able to attend all three workshops and found them to be of the highest quality."

Columbia County parent wrote that the workshops were the most informative she ever attended.

An experienced advocate and parent from Warren-Washington County said that the role play in which she participated, especially of the impartial hearing, helped her put the experiences of advocating for her own child into a very real and much less intimidating perspective. Incidentally this participant, Dahlia DelDebbio, not only is carrying on the project to her own chapter, but is now running training sessions for parents in her area serving on the Committee for the Handicapped.

The manner in which a network can

expand and the endless possibilities is an exciting outgrowth of this one pilot project.

The staff representative from Otsego County commented that seeing the process in action and being a participant in it were the most valuable training opportunities that she ever had.

The staff representative from Delaware County reported that the workshops were very helpful and informative, and that their parents were anxious to put their new knowledge to the test.

Sue Lyons who is on the staff of Fulton Chapter attributes a large part of her recent success in advocating for parents as a result of some of the skills she picked up at these workshops, as she was able to find some loopholes in the regulations of the Committee on the Handicapped and was able to help three individual parents to file for an impartial hearing.

WORKSHOP TITLES

Three workshops were conducted: "Stepping into Educational Advocacy," "Unravelling the Special Education Maze," and "Challenging Educational Decision." The participating chapters attested to the fact that they were creative, informative, and exciting because every individual attending participated, in some way in imparting information, experiences etc., as well as the outside experts who presented. The goals of each workshop were accomplished; i.e., (1) To cover basic advocacy skills and increase participants' awareness of parents serving as advocates; (2) Teach participants about individualized educational plans and Committees on Handicapped and (3) Addressing impartial hearings from the perspective of the parents' role in preparing for them.

The combination of discussion, interchange, and role play was an extremely effective technique in introducing new information and relating it to familiar experiences. In addition to having the expert Commission staff and outside experts, many of the chapter participants made presentations as well, bringing in real life situations.

From the Advocate's Desk

Dr. Frances Berko On Legislative Process

During the most recent session of the New York State Legislature, I experienced a period of maximum learning and, as is typical in all such learning experiences, I feel overloaded. All the lessons learned have not been absorbed. The legislative process is so intricate, unpredictable and, in some ways, nebulous that it defies description. As many of you have learned along with me, nothing can ever be assumed, no detail can be overlooked and what is true one day may not be valid the next.

I have a sense of great accomplishment. Laws were passed that hold real meaning for people with disabilities. The tremendous, constant efforts of so many people are the reasons why civil rights for persons with disabilities, independent living, the Office of Advocate's legislative base, respite, promotional opportunities under Section 55-b and the Mental Health Services Council were passed by the legislature. Yet, I feel some frustration, much like the student who received a final grade of B+ in a most difficult course and then realizes that with some additional effort an A could have been attained. At this moment, however, I do not know what that additional effort could have been.

In recent months, I have frequently asked, "Who is the enemy and why?" Why did the non-driver ID fail? It was needed by the disabled, the aging, the retail merchant, the restaurant owner, the parent. Proof was presented that fees would reimburse the state's start-up costs in less than one year. It was a governor's program bill. There were support letters from many diverse state agencies. In fact, the combination of agencies supporting this bill was a rarity in the annals of state government. It looked like "apple pie and motherhood."

Essential bills often fail to become law for reasons other than the merits of the bill or its financial impact. Both as a clinician and as a person with a severe disability, I believe that the most important initiatives pending before the legislature were the early childhood education bills. I would do anything to minimize the impact of disabilities on the individual, the family and the taxpayer. I know from personal experience that early intervention is the only way to do this. I know of no legislator, government official, service provider, teacher, early childhood educator or informed citizen who disagrees. After 14 years of a variety of proposals to begin to meet this need, neither pending bill had the universal support of all interested parties. In fact, both were drafted by consensus. It is hoped that, during the next session, a new approach can be presented

which will receive the support necessary for passage.

Too often, what is demanded is too much to have enacted at one time without a detailed, staggered plan for implementation. Equity demands that the rights of all New Yorkers, including all taxpayers and persons with all types of disabilities, be given equal consideration. It is a commonly known fact in capital cities of this nation that too frequently bills are passed in one house of the legislature with the prior knowledge they will never be reported to the floor of the other house. This "good buy - bad guy" has been played for years with some very basic legislation. Games will continue until we, acting in coalition, learn how to stop them.

In the last days of a regular session of the New York State Legislature, the pressure builds beyond description. In the waning hours of the legislative session, time often does not permit passage of essential bills by both houses, even when there is agreement that such legislation is necessary.

Finally, I am most grateful for the efforts which were expended by and on behalf of persons with disabilities during the 1981-82 session of the legislature. We have networked and wrought miracles. It would take an issue of the Advocate to list all the contributors to these joint efforts. While any partial list risks offending those who are omitted, I cannot resist showing off. Among those who acted together are the following organizations and their individual members: New York State Association of Retarded Children, New York State United Cerebral Palsy Association, the New York State Association of Rehabilitation Facilities, the New York State Legislative Coalition of Persons with Disabilities, the various local councils on the disabled and offices of the handicapped, Eastern Paralyzed Veterans Association and on and on ad infinitum. I applaud and thank each and everyone for a superb job.

Applaud reporters

News feature stories appearing in local papers around the state rate high in the opinion of the Public Information Committee.

Articles written by local reporters requested by local chapters and featuring the life-style of the mentally retarded at work and in community residences were developed into full page and half page spreads this past year. The Public Information Committee applauds in particular features in the Rural News, St. Lawrence County in May 1982 by Cheri Brothers; the Sunday Press, Binghamton, by Ann Treneman in August 1982; The Cortland Standard, April 15, 1982 by Barbara Grady, and the Watertown Daily Times, Jefferson County, September 1982 from Knight News Service.

These features represent, in the opinion of the Committee, positive steps towards community education. There are probably more out there which have not been called to our attention. A special recognition is due all the chapter people who promoted these excellent articles.

Robert Katz reports two intense and profitable fund-raising workshops, one in Albany and one in Buffalo area during October which were rated excellent by the participants.

Although the groups were not large, this allowed in depth discussion of particular problems for those who attended and the comments were that much technical assistance was gained by the participants.

They loved us in Sodus

August 26, 1982

Dear Willy, Ed, Charlie, Canmond, Eugene, Harry, Sydnea, Sarah, Donald, Dorothy, Helen and Francis,

The Sodus Chamber of Commerce would like to thank each and every one of you for being such helpful residents.

It's people like you that make a community nicer to live in. It has been noted on many different occasions that you folks (in the community residence) are out cleaning the sidewalks of litter or freshening up the flower bins when you go by.

You are very delightful people.

Sodus also enjoys having you attend all of our special events. We wish more people like you would get out and support our town.

Sincerely,
Sodus Chamber of Commerce
Sandra J. Wemesfelder,
President

Saratoga Peers Program helps parents talk

In an effort to provide a confidential atmosphere, where parents can feel free to discuss their feelings in a frank way, the Saratoga Association for Retarded Children recently began a Parents as Peers Program. Kelly Chabot, the social worker of the Day Treatment Program, has been leading the group since its inception.

Chabot said that until four years ago "there were lots of programs offered for children, but very little for parents." It was at that point that Mary Griswold, a psychiatric social worker from the Finger Lakes region, was hired to develop a program to address this need.

Parents as Peers, funded by the Office of Mental Retardation and Developmental Disabilities, is divided into three sessions, eight weeks each. Each group meets once a week for approximately an hour and a half. During the first few sessions parents get to know each other and develop new and lasting friendships.

Chabot said it is interesting to note how much the parents help each other. Some of the parents are young with small children, and others are older with adult children. He stresses that, while about 40 percent of the group is on Supplemental Security Income and have children under seven, "We want to reach parents who have adult children, too."

Confidentiality is maintained and the group is strictly for support — not therapy. "We provide the structure, but the group finds its own solutions," said Chabot.

Guilt is a topic that comes up during many of the discussions. Chabot said he tells parents: "It's OK to express those feelings and have the freedom to say 'I feel guilty' and not feel bad about it."

On "Fantasy Day", parents described what they would do if they had one day to themselves. Chabot said that they got to the root of a lot of problems and "had fun with it, too, and kept it light."

The next few meetings will focus on the parent-child relationship and how other members of the family deal with a handicapped child. The final sessions are mainly for review.

"We've been meeting at the Day Treatment Facility", said Chabot, "but we're willing to move if most of the people live farther south." Each group consists of 10 families. Parents must provide their own baby-sitting.

Chabot said that a mother who lives in Waterford summed up the feelings of many parents when she told him, "It's real hard for me to get up and know I have to drive up there. But when I do, I feel so good."

One Chapter president summarizes her office

Karen Kornreich has served as a director of Rockland ARC for over 6 years. She is the parent of a developmentally disabled child. A resident of Pomona, she is the mother of two sons - Brian - 11½ and Jeff - 8, and a daughter, Jaimie - 7½. Seventeen year old Joe also makes his home with the Kornreich family. Karen received her bachelor's degree from Adelphi and has a Master's in Speech and Hearing and in Special Education. She holds a professional diploma from New Paltz in Supervision and Administration. She is a Special Education teacher at Suffern High School where she runs the work-study program. Karen sees as the goals of the agency to increase membership and to make the agency more visible in the community.

Q: Why did you seek the presidency of ARC?

A: Because I care as a citizen, educator and a parent.

Q: How do you as a working mother of three children manage your time in handling such a monumental position?

A: I manage because I have a family who understands the importance of ARC and they're willing to eat a lot of fast food.

Q: What unique or different qualities do you bring to your office?

A: The strength of being a woman and the gentleness of being a mother. And most humbly, the depth by which I can understand and deal with the myriad of problems in an open and honest and sharing way.

Q: Are you frightened or concerned by what may very well be the most crucial year ever as far as budget cuts are concerned?

A: Not just for ARC, but for all handicapped organizations. The present cuts are JUST THE TIP OF THE ICEBERG. I feel that next year will be more crucial and we can plan via goals and objectives along money management lines to offset the problems we're going to face.

Q: What are some ideas or thoughts you may have on how to resolve the monetary deficits?

A: It is my hope that the Sheltered Workshop can become more self reliant through additional subcontract income, the ultimate long range being self sufficiency. We certainly need greater support from the private sector and it is my hope that industry will look at agencies like ours and feel a sense of responsibility to help us through these hard times, with financial support, jobs and contract. We need person power (volunteers) to help us with our fundraising activities.

Q: What is your philosophy of leadership?

A: I believe in the establishment at the onset of very necessary long and short range goals to be achieved through the working together by a very cohesive organization regardless of differences in personal feelings.

Q: What would you like to be able to say about your presidency this time next year?

A: That the agency I represent has managed to accomplish enough to set up new objectives and goals for the following year.

Q: What would you like others to say about you next year?

A: That it was a good year with a job well done.

Voting reg clarified

In October, Governor Hugh Carey signed into law a measure which states that a person cannot be denied the right to vote merely because of past mental problems or confinement to a mental institution. A spokesman for Sen. Frank Padavan Z.R. Jamaica, the measure's sponsor, said only a person's current state of mind could be considered to dispute his or her right to vote.

Joseph T. Weingold, commenting on the meaning of the phrase "Current state of mind" for the Public Information Committee, pointed out that this legislation is good legislation because it prevents stigma for past incompetence. "Current state of mind" means either a person is legally declared incompetent or not so declared.

Herkimer clarifies ombudsman project

Financial cutbacks in Human Service fields have affected disabled individuals in regard to the services they receive. The Client Assistance Project was developed to aid the client in obtaining these services. It does not function as an advocate program but as an ombudsman and mediator, which makes this project unique.

The Client Assistance Project (C.A.P.) is a statewide project sponsored by the New York State Office of Vocational Rehabilitation. It assists clients in obtaining benefits entitled to them under the rehabilitation Act of 1973 as amended by Title 1. The general goal of the Client Assistance Project is to provide advice and assistance to clients and client applicants in their relationship to programs and facilities providing services to them under the act.

Client Assistance Project's purpose is to improve vocational rehabilitation services and the client's utilization of those services. C.A.P. is oriented toward overcoming individual's problems in relation to the vocational rehabilitation system and addressing general concerns which exist within the vocational rehabilitation system itself.

The state has been divided into four project areas, each having a C.A.P. coordinator: New York City District - Paul Hearne, Just One Break 212-685-1626; Long Island District - Sandy Gottlieb, Center For Independent Living, 516-796-0145; Western District - Todd Eggert, Rochester Center For Independent Living, 716-275-0350. The Eastern District Office is located at and managed by Herkimer County Association For Retarded Children, PO Box 792, Herkimer, New

York 13350-0792. The office covers a 24-county region encompassing four new York State Office of Vocational Rehabilitation offices: Albany, Malone, Poughkeepsie, and Utica.

Problems or concerns may be referred to the project by any source. Misunderstandings or differences of opinion might arise between an office of vocational Rehabilitation client and the local office of vocational Rehabilitation office staff. C.A.P. may be contacted if an individual has concerns regarding the length of time it takes between the application and the beginning of services, confusion of why a person's case has been closed or the status changed, or if the person feels he did not receive services or equipment he thought he was entitled to. These are just a few examples. C.A.P. concerns are directed primarily to the needs of individuals and their relationship to the service delivery system, the Office of Vocational Rehabilitation.

The cooperative working relations developed between Office of Vocational Rehabilitation offices and the C.A.P. offices have produced positive results for both the client and the Vocational Rehabilitation staff. The client assistance coordinator for the Eastern district, Cheryl S. Gifford, keeping generally within the ombudsman and mediation role, may be in touch with a variety of agencies on specific concerns. Agencies and facilities may be interested in consulting with the project from time to time in an attempt to resolve problems which clients may be having in regard to their services.

Clients who may need assistance should be made aware of the project's existence.

Irene Platt is ARC President (Continued from Page 1)

— A resolution on responsible advocacy for the mentally retarded who expressed a desire to register and vote was passed. The resolution asked that programs encouraging registration and voting be designated to include training in Civics, Public Affairs Programs on TV and discussion to enable the mentally retarded to exercise their voting franchise as intelligently as possible.

— A resolution pertaining to the education of children residing in developmental centers was passed and expressed the need for parents to be accurately informed of the procedure to secure educational services for their children.

INSTALLATION AND APPOINTMENTS.

Officers installed for the coming year are:

President	Irene L. Platt, Esq.	(N.Y.C. Chapter)
Vice-President	David Lettman	(ERIE Chapter)
Western Region & Sr. Vice-President		
Vice-President	Bernice Volaski	(WELFARE LEAGUE)
Southeast Region		
Vice-President	Shirley Valachovic	(SCHENECTADY)
Northeast Region		
Vice-President	Richard Marcil	(BROOME-TIOGA)
Central Region		
Secretary	Shirley Reynolds	(WEST SENECA)
Treasurer	George G. Hirsch	
Assistant Treasurer	Ann McDonnell	(WESTCHESTER)
Immediate Past President	Eleanor C. Pattison	

Members of the Executive Committee elected by the assembly were, in addition to the above, Henrietta Messier, Rensselaer Chapter, Dr. Irving Caminsky, Rockland Chapter, and Regina Black, Orange Chapter.

These Chairpersons for committees were appointed after convention by President Platt:

Budget & Finance	Robert Meltzer	(WESTCHESTER)
Community Residence	Elliot Aronin	(NASSAU)
Education	Ellen Maroun	(FRANKLIN)
Developmental Center	Betty Pendlar	(N.Y.C.)
Guardianship	Bernice Volaski	(WELFARE LEAGUE)
Insurance/Pension	Jerome Ness	(SUFFOLK)
Legal & Legislative	David Wilkie	(RENSSELAER)
Sub-Committee on Legislation	Warren Heilbronner	(MONROE)
Prevention	Eleanor Pattison	(RENSSELAER)
Public Information	Joan Edwards	(ERIE)
Scholarship & Awards	Kate Klein	(ST. LAWRENCE)
Voc Rehab	Kay Nogaj	(MONROE)
Youth	David Essrow	(ERIE)
	Maythorne Winterkorn	(MONROE)

Nominating committee Chairperson to be appointed.

Overheard during dinner at Convention "after all, what else is there to life but MUSIC, POETRY, POLITICS, RELIGION AND ARC?"

Brain bank solves brain puzzles

For more information, and for donor forms and cards, write to either of the two brain banks supported by the National Institute of Neurological and Communicative Disorders and Stroke:

W.W. Tourtellotte, M.D., Director National Neurological Research Bank, Human Neurospecimen Collection, VA Wadsworth Hospital Center, Los Angeles, California 90073.

Edward D. Bird, M.D., Director, The Brain Tissue Resource Center, McLean Hospital, Belmont, Massachusetts 02178, (617) 855-2400 (May be called 24 hours a day, collect)

(The following telephone numbers may be called collect. Ask for Dr. Tourtellotte, or leave a message and your call will be returned). Brain Bank: (213) 824-4207; FTS 794-4171; VA HOSPITAL: (213) 478-3711 (phones answered 24 hours a day).

The human brain is by far the most complex organ of the body. It is also the most difficult organ for medical investigators to study. They cannot get at it (except during major surgery) during a person's life, and it is usually unavailable to them after a patient has died. Yet, according to the National Institute of Neurological and Communicative Disorders and Stroke, an adequate supply of both normal and diseased brain tissue is essential for research that will finally conquer neurological disease.

NORMAL BRAIN TISSUE ALSO NEEDED

And it is not only from those with brain disorders that tissue is sought. Both brain banks also need donations of normal brain tissue to use when scientific work requires comparison of normal and abnormal samples.

Normal tissue can be donated by anyone — but it is usually the most difficult to obtain. Often families of people with neurological disorders, recognizing the great good to be gained from future research, will designate themselves as brain tissue donors. But the National Institute for Neurological and Communicative Disorders and Strokes hopes that other, non-involved members of the public will also recognize the need and take steps to assure donation of their brain tissue following death.

Dr. Tourtellotte, who in addition to directing the Los Angeles brain bank is professor and vice-chairman of neurology believes that the best way to get brain tissue donations is to appeal directly to patients and their relatives.

Tots, tics, Tourette

In a recent study conducted at Yale University it was found that 15 out of 100 children who were given stimulant medication for symptoms of attention disorders developed irreversible Tourette Syndrome as a result of the medication.

Researchers indicated that because early signs of Tourette Syndrome are difficult to distinguish from hyperactivity and attention disorders, clinicians may prescribe stimulants such as methylphenidate (Ritalin), pemoline (Cylert), and dextroamphetamine sulfate, which can intensify tics in children already susceptible to Tourette Syndrome. And these symptoms do not subside once the stimulants are discontinued.

Researchers recommend that children and their families be fully screened for tics and Tourette Syndrome before any stimulants are prescribed — and that where such symptoms are detected in either the child or his family, stimulants not be considered in treatment.

For more information about Tourette Syndrome contact: Tourette Syndrome Association, Inc., 41-42 Bell Boulevard, Bayside, N.Y. 11361, (212) 244-299.

— Seattle Washington Newsletter, Assn. For the Severely Handicapped.

"These are the people who have the strongest desire to support brain research," Dr. Tourtellotte says. "There is no substitute for brain tissue donations from patients and healthy individuals. There can be no more sincere or valuable gift to mankind."

HOW TO GO ABOUT DONATING BRAIN TISSUE

Anyone 18 years of age or older and of sound mind may become a brain donor simply by signing an organ donation card. The under-18's may do so if a parent or guardian gives consent. Even if a potential donor cannot sign a card, but has given no indication that he would not want a donation made, the next of kin may give consent. A husband or wife, adult son or daughter, either parent, adult sister or brother, a guardian, or any one authorized to make arrangements following death are considered next of kin for this purpose.

Donor forms and cards may be obtained from the brain banks (see boxed addresses). The donor cards, once filled in and signed, should be carried at all times. The family and the physician should also be told of the future donor's wish to give his brain to scientific research after death.

The decision is not irrevocable, however, and a change of mind can be followed through by destroying donor card, and by informing the physician and the family.

Removal of brain tissue can be accomplished without affecting funeral arrangements in any way, the Institute spokesmen note, and it leaves no visible scar.

In certain cases the Institute's brain banks may pay part or all of any autopsy expenses associated with the donation of brain tissue, but this would have to be worked out in advance. In many hospitals, however, there are no autopsy fees.

The brain banks do accept all costs of handling the donated tissue following the autopsy, but they cannot pay any funeral expenses, nor will they pay donors or families for brain tissue.

(This article was written from materials supplied by the National Institute of Neurological and Communicative Disorders and Stroke, Bethesda, Maryland).

Down's Syndrome and cosmetic surgery

Until recently, it can be said that persons with Down's Syndrome, a chromosomal abnormality often resulting in mental retardation, were marked for life.

Despite advances in education and training techniques which have enabled them to function at nearly normal levels, individuals with Down's Syndrome are labeled as retarded because of their appearance.

Today minor plastic surgery can be used to make these people less noticeably different from their neighbors in society. According to a recent New York Times article (August 31, 1982), more than 250 Down's Syndrome children have had their appearances altered through plastic surgery.

Two plastic surgeons, who began performing these operations in 1977, Drs. Gottfried Lemperle and Dorin Radu, generally reduce the size of the child's protruding tongue, bring the ears closer to the head, alter the axis of the eyelids, raise the bridge of the nose, cheekbones and hanging lower lip, and, in some cases insert implants in severely receding chins.

The surgeons state that the procedure is inexpensive, leaves no visible scars and is virtually risk-free.

It has been noted that Down's Syndrome children who have undergone these operations have exhibited improved behavior, higher self-esteem and have made great strides in social development.

(— Intercom, September)

Site selection procedure

Albany — OMRDD's public education bureau and speakers bureaus at Developmental Disabilities Services Offices throughout the State are offering a free brochure detailing the Site Selection law's procedures for establishing community residences for the mentally ill and mentally retarded.

Originally produced by the Office of State Senator Frank Padavan of Queens, author of the legislation, the informative brochure is being reproduced and distributed with permission of his office.

"New York's site selection law strikes a delicate balance between the rights of the mentally disabled to community-based care, and the rightful concern over

community stability. Its step-by-step process, as carefully spelled out in our publication, should be of interest to all those concerned about how the community residence program operates in their neighborhood," Sen. Padavan said.

NEW YORK'S SITE SELECTION LAW: A guide to the Process for Establishing Group Homes for the Mentally Disabled is available free of charge and in any quantity desired to local governments, civic groups, advocates for the mentally disabled, and other interested parties. To order, simply write: OMRDD, Public Education, 44 Holland Ave., Albany 12229 or to 'Speakers Bureau' at the Developmental Disability Services Office that serves your community.

Tragedy triggers two way training

Less than a year ago the New Jersey Association for Retarded Children reeled under the impact of the suicide of a retarded man. An employee in the maintenance department of the Hunterdon Medical Center was taken into custody by Raritan Township Police and charged with having made an obscene remark to a 14-year old boy. He was eventually released by police. When returned home he took his own life, authorities reported.

Huntingdon ARC Executive Director at that time, Joan Crawford, told the Community Services Council following the incident that somebody should have explained the offense to the retarded man, the 40-year old son of one of the founders of the Huntingdon County ARC. "Because he saw the arrest as such a terrible offense, such a terrible burden to his family, he could no longer live with it," Crawford told the group, according to a news report of the meeting.

ARC WORKSHOPS FORMED

Following the tragedy, workshop sessions on Behavioral Do's and Don't's in encountering professional law enforcement authorities have been developed and operated in the New Jersey ARC to teach the mentally retarded ways to respond in contacts with police.

ARC WORKSHOPS FORMED

These situations do not have to be frightening, derogatory, or demeaning for people who have acquired the basic skills of conduct for such contacts, police professionals maintain, according to Kevin May, Criminal Justice Education Project Director.

The workshops enlarge on understanding and keeping the individual's rights while helping him cooperate with the police or other criminal justice professionals to the greatest possible degree.

AUTHORITIES ORIENTATION

FBI Enforcement Bulletin for September 1983 reports the kind of education police receive to understand their role in the case of the mentally retarded child. Martin A. Greenberg, J.D., Assistant Professor of Law Enforcement, Arkansas State University and Ellen C. Wertlieb, Ph.D., Assistant Director, Special Learning Center, College of the Ozarks, Clarksville, Arkansas explain the training in the FBI bulletin. "Today's police officer is required to enforce the law in situations that are more and more complex."

Such complications arise, the bulletin states, whenever a mentally retarded person violates the law. However, low intelligence itself does not play an important role in causing delinquency, unless this factor combines with other factors such as poor home environment, alcoholism, mental disease, parental or guardian discord, low socio-economic status, or community rejection towards children.

TECHNIQUES FOR HANDLING

Before police officers can know how to

handle cases involving mentally retarded children, they must be familiar with the characteristics of mental retardation. This premise is the basis for education of police and enforcement people.

Techniques for handling mentally retarded children were described in the long report which is only partially reported in this article.

(1) A positive and direct response to teach subject will enhance the overall ability to cope successfully with the mentally retarded child. An officer can best prepare himself for undertaking such a response through an understanding and appreciation of the difficulties faced by the retarded child.

(2) The police officers should be very clear and specific in any directions given. For example, if the child is told not to display certain behavior on a street corner, the retarded child might go to another street corner and display the same behavior if it is not clearly explained that the behavior is not appropriate in any public location.

(3) Simple language should be used when talking to the retarded child. In addition, the child should be asked to explain what was just said. Although the child might respond in the affirmative when asked if everything was understood, this might not be the case — he might respond with the word "yes" to almost anything that is asked.

(4) Since retarded children often have difficulty in expressing themselves verbally, insistence on such a response might be very frustrating and frightening. Consequently, the use of visual aids, such as pictures, might be very helpful in explaining things, as well as in obtaining responses.

(5) Retarded children should be given the same respect as other children. They should not be treated with ridicule or pity. In addition, they should not be treated as if they were not present when a third party is being consulted.

(6) Expect the mentally retarded individual to act in a manner which would be more appropriate to someone younger than his age, such as sudden temper tantrums, or the refusal to respond because of fear or shyness. The level of maturity will depend upon the degree of retardation.

(7) When a police officer must make contact with the child's parents or guardians, he should not hold any preconceived notions as to the type of care given to the child. The parents should be approached in a positive and direct manner regarding the specific incident. When appropriate, the officers should provide the parents with the name of local agencies that provide supportive services to the retarded and their families.

The bulletin concludes that due to their limited ability to cope in some situations, retarded individuals are often among the citizens who are most in need of a police officer's services.



Ray Lawandowski, Executive Director of the Madison County ARC, tips his hat in spirit of celebration as Lois Jones, President and Kammy Lynn Rudd look on.



Marc Brandt, NYSARC Executive Director, greets ARC supporters at Harvest Hoe-Down.



Lois Jones, President, joins 2 winning ladies: Christine Garneau, 1982 Jonathan T. Weingold Scholarship winner and Kammy Lynn Rudd, Miss New York.

Madison Harvest Hoe-Down

Kammy Lynn Rudd, recently crowned Miss New York in the Miss Nation Beauty Pageant, was one of the featured attractions at the Madison County Association for Retarded Children's "Harvest Hoe-Down".

Miss Rudd earned her title on the basis of beauty, poise, personality, scholastic, and civic activities.

The multi-talented twenty-year old was valedictorian of the 1980 class of Jordan-Elbridge High School and is studying languages and biochemistry toward a career in pharmacology or international pharmaceutical sales. She is presently employed as a modeling instructor at the Barbizon School of Modeling in Syracuse.

Miss Rudd, who has studied tap, jazz, and ballet for 17 years, has entertained for the Cayuga County Association for Retarded Children in Auburn and was a drum instructor in high school for Special

Education students.

The evening featured good food and foot-stomping music and a program of varied attractions. Highlighting the evening's program was Peterboro resident Dot Wilsey and her program of life-size puppets, "Kids Matter." Miss Wilsey has achieved national renown among educators and human service workers with her creative techniques in addressing social issues.

The charming and inspiring puppet presentation, "Kids Matter," involved the adroit and inconspicuous manipulation of life-size puppets of handicapped and school-aged children "getting to know each other." The presentation was clever and thought-provoking, and the puppets had distinct and lovable personalities. Wide interest was expressed by the audience in the availability of "Kids Matter" to schools and other chapters.

Prevention: Reagan Alert

Fred Krause, executive director of the President's Committee on Mental Retardation, said that "at least 50 percent" of the 164,000 new cases of mental retardation each year could be avoided by a combination of genetic counseling, pre-birth screening of high-risk parents, prenatal genetic diagnosis, screening of newborn infants and early treatment of affected children.

Krause said 6.5 million Americans — 3.5 percent of the population — suffer some degree of mental retardation. The federal government spends \$4 billion a year on 52 programs for the mentally retarded, and Krause said that the lifetime care of a mentally retarded person costs at least \$1.5 million in tax money and could cost double that.

Krause said that genetic counseling would provide information with which parents then could make up their own minds about what steps to take. "There is no case I know of," Krause said, "where the patient says to a doctor, 'I want to have a defective child.'"

These are his suggestions for reducing the frequency of mental retardation:

Genetic counseling. In this service, trained professionals analyze the risk of genetic disease among people, for

example, who have a family history of birth defects or genetically caused disease.

Screening of newborns. Certain diseases, such as PKU, an inborn metabolic absence of an enzyme, or congenital hypothyroidism, which frequently causes retardation, can be diagnosed by testing a sample of a newborn baby's blood, and dietary treatment can be started before brain damage begins.

Common sense precautions. These include keeping babies away from brain-damaging lead in paint, ceramics and magazine pages, and making sure babies are strapped into car seats when in automobiles. Children of migrant farm workers, Krause said, sometimes eat clay, which contains pika, a chemical compound that can damage the brain.

Genetic diagnosis. These are tests on a fetus to provide information to parents on the chances of having a defective baby. Techniques include radiography, ultrasound and — most commonly — amniocentesis, which involves inserting a needle into the womb of the pregnant woman and withdrawing amniotic fluid, which can be analyzed for abnormal conditions.

Med students learn about MR

Upon completing their first year at New York Medical College, John Holter and Janet Lin came to work at LV during the summer so that they could learn more about providing medical services to the developmentally disabled.

As part of an educational program designed and coordinated by deputy directors Jack Sobel and Barbara Kenefick and Dr. Cimino of New York Medical College, students are encouraged to participate in a non-credit employment experience at LV during the summer months.

This year, two students worked in the Skytop unit under Dr. Hector Quesada and nurse practitioners Edna Novano and Irene Colter. They accompanied Dr. Quesada on his rounds, helped perform physicals and other routine medical care, attended a lecture given by LV psychologist Dr. Hy Rothstein, toured the Genetics lab and the Med-Surg Building and pursued library research on selected topics.

"I had never been in a facility for the mentally retarded and you don't receive much exposure to the topic in the classroom," said John Holter. "My summer here has given me a different

perspective on mental retardation."

According to Dr. Sobel, the program was designed to give more medical students exposure to medical practice in an institutional setting and the different problems a mentally retarded patient can present to a practitioner. "As the movement towards deinstitutionalization of developmentally disabled clients continues, physicians and other health care providers will find that more and more of their patients require special care," said Dr. Sobel. "We hope that this and other programs offered at LV will acquaint students in all fields of medicine with the needs of the developmentally disabled," he added.

Janet Lin felt that her summer on campus was a "terrific experience." "The program was very successful in presenting how providing medical care to developmentally disabled persons differs from providing care to the general public," she added.

"It was a pleasure to have the two students join us in Skytop unit, they were very helpful and efficient," said Dr. Quesada. "I hope they have benefitted from the program."

(Intercom, September)

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