

Our Children's Voice

Retarded Children Can Be Helped

VOL. XXXIV NO. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

JUNE 1983

Brandt alert on budget shortcomings

"It could have been worse but it is not good." Executive Director Marc Brandt summarized the budget effects in reporting the 1983-84 state budget passed by the Assembly and Senate and signed by the Governor.

"We were successful in a number of areas due to your support and concern but the battle is just beginning..." he told association representatives. Programs for the Mentally Retarded were restored. But had the budget as presented by newly-elected Governor Cuomo been approved, it would have set in motion drastic effects on the lives of the mentally retarded of New York State.

The Governor's proposed budget was misleading and in many instances required a stronger county participation of funding programs for the mentally retarded. The budget called for the closing of Craig Developmental Center without really addressing the appropriate humane placement of the 450 residents of Craig Development Center. In addition, the Governor's budget called for drastic reduction of state staff needed to support thousands of mentally retarded individuals who have successfully been placed in community settings.

It appeared to our Association that improved programs for the prison population were being proposed at the expense of service to the mentally retarded and other disabled groups. It also appeared that as the State of New York assumed the local share of Medicaid, non-Medicaid programs funded currently at 100 percent by the State of New York would be moved to the traditional county local assistance formulas requiring less financial participation by the state government. Although there were many areas of serious concern in the Governor's proposed budget for the New York State Office of Mental Retardation and Developmental Disabilities and the New York State Office of Vocational Rehabilitation, the New York State ARC focused its attention and efforts with the Legislature on the following: Community Residence Programs, Developmental Center Programs, Direct Sheltered Workshop Programs, and Leased Space and Capital Projects.

Through the collective efforts of our 64 Chapters, our Association was successful in convincing the Legislature to restore many of the Governor's proposed reductions.

Offices move to Albany area

Board approves new location for NYS ARC

At the March meeting of the Board of Governors, purchase of Adams House from the Town of Bethlehem for \$115,000 was approved. This action set in motion plans for a new administrative site for the New York State Association for Retarded Children Inc. (NYSARC). The purchase "creates a place for NYSARC that will belong to every member" Marc Brandt, Executive Director, told the board. "It can be our Information Center, meeting place and library and will be an administrative asset to the association" he said, referring to its short distance to the Capitol and Legislature in Albany. Renovations which will not affect the potential landmark quality of Adams House are planned.

"We take our own important history with us wherever we go," Brandt said. "NYSARC, which has been located in one of New York City's Historic Landmark buildings, the Flatiron Building, will have a permanent home free of escalating rent costs. Our association over the past 34 years has become one of the strongest, most influential organizations of its kind in the United States," he said. "We have a proud tradition. Our accomplishments can be seen within our 65 chapters as the quality of life for the mentally retarded has significantly improved in New York State."

PREVIEW OF NYSARC DIRECTIONS

"Although our association is proud of its past accomplishments, we must develop corporate management techniques so our gains will not be undone," he admonished the state board. "We are not managing for

managing's sake," Brandt said, "and no systems will be proposed that are not consistent with the policies and philosophy of our association. What we will do is improve on the kind of assistance offered in the past to reinforce our goals. In the early stages of NYSARC, there was little need for a staff at the state level. The mandates of the association were best addressed by the small competent staff employed. Today our association operates 64 chapters both in the community and developmental centers with a wide range of programming. Additional staff is required."

"Combined budgets of these programs for the state in 1981 totalled over \$113,779,197. Although successful, our organization cannot be measured in dollars alone," Brandt said.

PRIORITIES EXPLAINED

Priority for NYSARC now is to develop a management system within the corporate structure which exists to allow for two main components — Legislation and Technical Assistance to Chapters.

Our Legislative Platform will continue to be reviewed and adopted at our annual convention. Our technical assistance to chapters will expand so we shall provide a full range of assistance in the areas of quality assurance, fiscal management, legal consultation and training. In asking for more staff, Brandt explained that hours of staff time are consumed in resolving chapter problems, some still in the process of being solved. Other requests for assistance include real estate tran-

sactions, holding corporations, depreciation schedules, certification reviews, special incidents, management problems, labor - related situations, program development, cash flow problems and money management, legal consultations and a variety of others.

"Staff is selected first on the basis of dedication to the services for all our mentally retarded," Brandt said, "and according to professional abilities in the field."

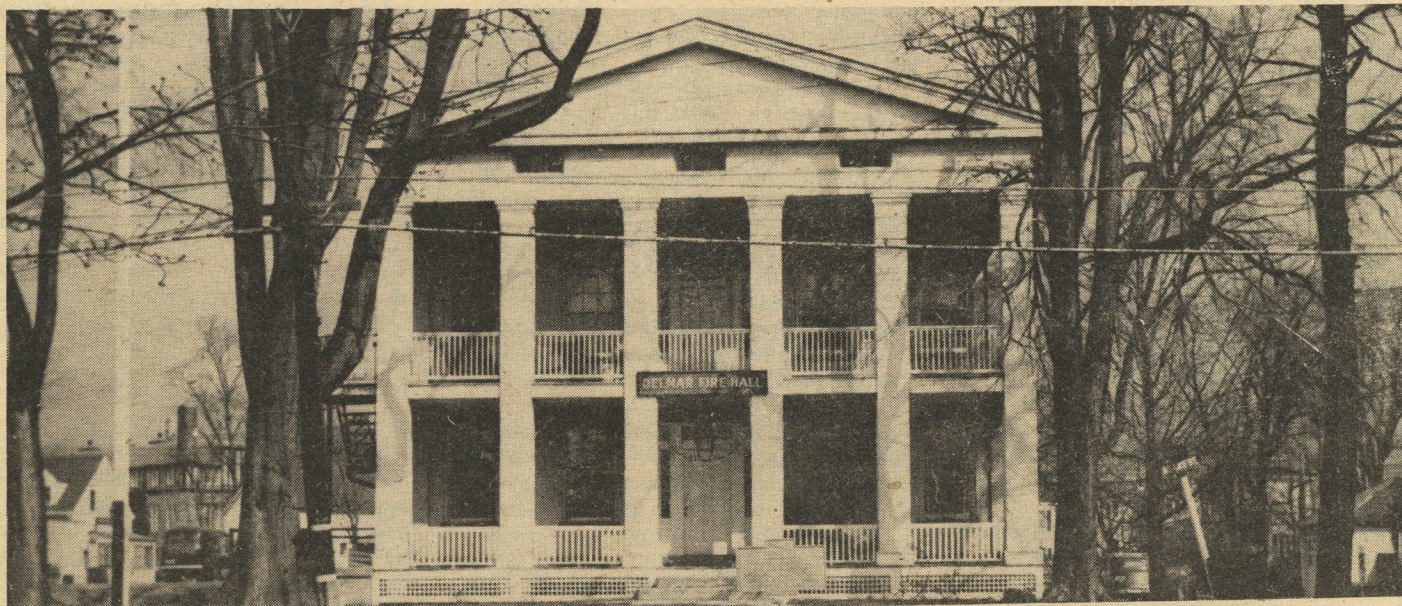
ASSESSMENTS CLARIFIED

Of particular interest to chapters is the change in definition of assessment. Effective June 1, 1983, the term "assessment" will be changed to "administrative charge". It is clear that the term assessment is no longer applicable (in its connotation of tax) in the proposed structure for technical assistance to chapters.

"In essence," Brandt explained, "the association is the corporate entity. State ARC will assist all chapters upon request in obtaining reimbursement for this Administrative Charge through local assistance or direct state contract budget considerations with the Office of Mental Retardation and Developmental Disabilities and with the counties they represent."

Marc Brandt stressed the changing role of NYSARC. "Our association is complex," he told the Board of Governors. "All members need to understand and support the important role we play in the affairs of all who are mentally retarded."

NYS ARC's grass roots Delmar home



Historic Adams House in Delmar, N.Y. was approved for purchase by the Board of Governors at its Spring meeting in Albany. This eighteenth century building was built by Nathaniel Adams as a stagecoach wayhouse on the Albany Plank Road to Schoharie. It was one of the first post - patroon structures not leased - owned by the last wealthy patroon of Rensselaerwyck,

Stephen Van Rensselaer. Adams House on the Delaware Turnpike was the first Village Post Office in 1939 before the Federal Post System in Washington created its rural mail system. Nathaniel Adams was Waystation Manager for the early coaches and pony express was the first Postmaster. It is located at 393 Delaware Avenue, Delmar, N.Y.

NOTE OUR NEW ADDRESS:

New York State
Association for
Retarded Children, Inc.
393 Delaware Avenue
Delmar, New York 12054
Telephone: 518-439-8311

A Salute to Parents

by Gerry Sherwood

Involvement in the field of Human Services is probably one of the most absorbing and demanding of all possible service areas, for it is here that we, as parents and professionals, encounter an ever present requirement for high level competence and commitment, and the need for continual replenishment and renewal.

Regardless of whether our involvement in mental retardation has been the result of fate or is the result of personal choice, all of us have shared common experiences characterized by a peculiar admixture of utter frustration mercifully balanced by exciting moments of elation when progress toward our goals is achieved.

It is this sense of "experiencing" and "sharing" that has meant so much to me

as we have worked together. During these years I have collected a treasury of memories — some happy, some sad, but all personally and professionally enriching, and for this I express my gratitude.

It is not possible to write an individual farewell to each of you and so I take this occasion in my last issue to OCV to do so. Having had the opportunity to serve you and your children has added a dimension to my life for which I shall always be grateful. I want you to know that although I am leaving the Association, my thoughts and interests will always be close to you.

May we see in the not too distant future the results of our mutual efforts manifested in a more hospitable world where those we serve can live, grow, work, participate and experience love in an atmosphere of true acceptance.

LETTERS to the EDITOR

Dear Editor:

Much time has elapsed since the one and only meeting of the Committee set up by Governor Carey to Monitor the findings of the Commission on Prevention of Mental Retardation and Developmental Disabilities, but we still see no tangible movement on most of the recommendations of the Commission.

High on the list of such recommendations is the creation by the Legislature of a Temporary Commission on Prevention. Such a bill was introduced but got nowhere.

We cannot believe in the sincerity of the Governor's Office or other Departments concerned (Health and OMR-DD) unless such a measure becomes part of the Administration's Legislative program.

The struggles of the Sub-committee of the New York city Conference-Prevention, etc. and that of the Western Region under Dr. Guthrie are laudable, indeed, but obviously ineffective since they are without power.

History has shown over and over again that the Legislative branch must ride herd on the Executive where definite action is called for, as in Prevention. The Legislative alone has that power.

We urge that the measure be reintroduced as an administration item — and passed — This must not be another example of pious wishes, well intentioned proposals and cynical neglect.

Joseph T. Weingold

Dear Editor:

The honest and frank letter by Joseph T. Weingold that "ARC Without Parents is An Agency" struck a chord with me. As an advocate for mental health for more than twenty years, I have seen too many parents who lend themselves to the voluntary aspects of an organization, but in most cases only for the "What's in it for me attitude." Of course, that attitude is for their particular son or daughter or relative or for their own ego and vanity; but still with knowledge comes advocacy, and with advocacy — comes change and results. This poem was sent to me, many years ago and I want to share its thoughts as a compliment to Jerry Weingold — a true advocate.

A MAN

Give me a man, not too good and not too bad

A man who works for the interests of the many in preference to the few;

A man who makes strong friends and powerful enemies;

A man who makes his position clear on questions without fear to criticism;

A man who would rather fight clean but who is willing to use a little fire when fighting the devil;

A man who can with charity to the vanquished and love with bitterness toward none.

Such a man, I am proud to call my friend and true advocate.

Respectfully submitted,
Jerry Rosenblatt

Dear Editor:

May I bring to the attention of our readers the value of active politicking?

Not often considered by advocates as a route of persuasion is the role of the enrolled party member. The question is — Does your political party support Mental Retardation Legislation?

Although a large segment of the voting public prefers to remain unenrolled, according to statistics from Boards of Elections, it is important to note that voters have a right to remain unenrolled but that by doing this they give up the opportunity vote in the primary elections — thereby influencing the selection of candidates; also they give up the opportunity to serve as delegates to designating conventions.

Unenrolled voters cannot run for office unless they have formal approval from a central executive committee; they cannot sign designating petitions and cannot vote in party caucuses.

Because of the State Legislature's delay this year in completing the political calendar, persons who decide to enroll in a party won't be able to vote in primary elections this Fall.

State law says enrollments in political parties aren't effective until after the general election in November. Enrollments made now will be effective for next year.

A political party reflects the consensus of its members. Could this be a missed opportunity in your area?

Kate Klein

I AM ME

I have Dreams
I may be fatherless and handicapped but,
I have a mother to love and friends who care about me.

I have two sisters and nieces and nephews who I love and who love, and care for me.

I am happy that I am me.

By Allan Askkensas. Model for the bronze sculpture commissioned by AHRC, New York City Chapter and presented to Pope John Paul for exhibit at the Vatican. Allan is a young man from Manhattan who is mentally retarded. He was thrilled to be the subject of Judith Weller's creation.



Honored Service

Leo Samson of Rotterdam, front right, receives an Honorary Membership in the Schenectady Association for Retarded Children from ARC President, Bella Stuart, with Board Member, Paul Robinson, rear left, and Executive Director Carl Hawkinson, rear right, looking on. Samson was honored for his service as State Chairman of the Annual Knights of Columbus fund events to benefit programs for Retarded Children.

(Schenectady Gazette Photo)

Survey supports prediction

Upon accepting his appointment as Executive Director of NYSARC, one of the first statements made was to the effect that, in prosperous times, people are generous to the handicapped but that NYSARC must plan a large fund-raising future given the state of the economy.

This alert was born out in a study done by the American Association of Fund-Raising Counsel, a leading authority on philanthropic trends.

According to the association's estimates, giving from companies and foundations brought the tentative total of charitable contributions to \$59.8 billion. It said this figure could climb to \$60 billion before the books were closed on 1982.

But no prospect was seen by the

association that private contributions could make up for the reduction in federal financial support for the country's 300,000 non-profit organizations active in education, health, social welfare and the arts.

And while individual donors gave 9.4 percent more, the association said this compared with an increase of 11.9 percent in individual giving a year earlier.

In the midst of a severe recession, individuals, companies and foundations gave nearly \$60 billion to charity last year, more than ever before.

But despite the generous giving, the rate of increase slowed, just as it did in the downturn in the mid-1970's the survey indicated.

Our Children's Voice

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Thank you celebration for Ellie Pattison

On Friday, January 14th, over 170 people, representing ARC Chapters from throughout New York State, gathered at the Turf Inn in Albany to say "thank you" to Ellie Pattison.

In addition to the usual cocktails, dinner and dancing, everyone was given an opportunity to share memories of some of the more unique moments of Ellie's four years as President of the New York State Association for Retarded Children.

—Chuck Hayes, Executive Director of the Essex ARC, recounted how, at an open house for a new community residence, Ellie mistook some neighbors for new residents of the group home.

—Kate Klein of the St. Lawrence County Chapter used song verse to tell of a particularly harrowing trip on the Northway, involving Ellie, Henrietta Messier and Geraldine Sherwood, in which the muffler, front seat and headlights all gave out.

—Ellen Maroun, who served as Northeast Regional Vice President during Ellie's Presidency, described the time Ellie ran down the runway of the Franklin County Airport to stop a plane from taking off without her.

—Rensselaer County Unified Services Commissioner Ara Baligian related his experiences as Ellie's dancing partner in an 18 hour dance marathon to raise funds for the ARC.

—Sue Eisler Roberts, who formerly worked for OMRDD, described the time Ellie flew around the state, during the snowstorm, unable to land for several hours. When her flight was finally able to land, Ellie made her way carefully from the airport only to find the meeting had been canceled due to bad weather.

—Current State ARC President Irene Platt told of the whole new dimension that had been added to her legal practice as a result of Ellie talking her into assisting with a hearing before the New York City Taxi Board.

—Jim Flanigan, Executive Director of the Rensselaer ARC, recounted the time Ellie and Henrietta Messier chose to take a stand on principle at one of Albany's finer restaurants.

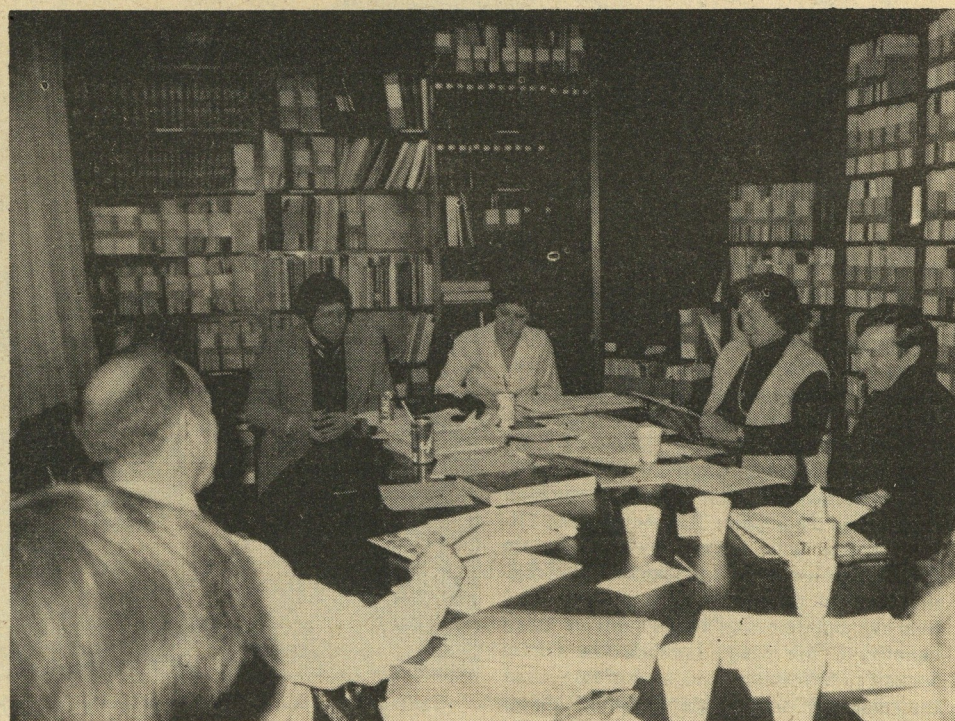
—Joe Killeen, former President of the Rensselaer ARC, told of the time Ellie lost her contact lenses only to find them in an embarrassing place.

Throughout all these stories one common theme could be found, the enthusiasm and commitment with which Ellie takes on the challenges presented her in life. Henrietta Messier concluded the evening's presentations by telling how this enthusiasm and commitment had benefitted mentally retarded children and adults throughout New York State.

Earlier in the evening Ellie was presented an album of letters from ARC Chapters from around New York State describing plans to plant trees, shrubs and flowers to her name. People who knew of Ellie's love for these things had suggested that this "growing tribute" might be the most fitting way to say "thank you" to a person who had done so much for the Association for Retarded Children. The fact that this tribute will continue to grow and provide beauty in the lives of so many people could be seen from the care and thought that had gone into many of the letters.

Comments from those in attendance indicated that the thank you celebration had been a most fitting and unique way of recognizing someone who had been so special to the ARC.

Residence Committee at Work



Facing: Joseph Kovler, Associate Director NYSARC, Chairperson Ellen Maroun, Anne Krause, Co-Chairperson - Community Residence Committee and NYSARC Executive, Marc Brandt.

Medicare rehab expanded

A new regulation expands the scope of benefits under Medicare's medical insurance to include services furnished by comprehensive outpatient rehabilitation facilities. The new rule is designed to enable beneficiaries to receive coordinated comprehensive rehabilitation services at one location rather than having to go to different sources.

Previously, Medicare covered certain rehabilitation services in a variety of settings, including services furnished as part of a doctor's treatment or out-patient physical therapy or speech pathology services furnished by a physical therapist in independent practice. The new rule establishes the comprehensive outpatient rehabilitation facility as a distinct type of facility.

Under the new rule, Medicare medical insurance will help pay for services furnished by a comprehensive out-patient rehabilitation facility if the beneficiary meets the following conditions: 1) needs skilled rehabilitation services, 2) a plan for treatment was established and is periodically reviewed by a physician, 3) the services were furnished while under the care of a physician. In addition, the services must be furnished on an out-patient basis by a physician or other qualified personnel in a rehabilitation facility approved by Medicare.

The regulations implement provisions of the Omnibus Reconciliation Act of 1980 (P.L. 96-499). They were effective as of December 15, 1982. However, facilities cannot be reimbursed for services under this provision until they apply for participation in Medicare, are surveyed, and are found to be in compliance with the conditions of participation.

Services that may be covered by Medicare medical insurance under this provision include physicians' services, physical therapy, occupational therapy, speech pathology services, respiratory therapy, prosthetic devices, orthotic devices, social services, psychological services, nursing care, drugs and biological supplies, appliances, and equipment for use in the facility. In addition, all services must be performed at the facility, with the exception of a visit to the patient's home to determine the potential impact of the home environment on rehabilitation goals.

The regulation specified that any of the listed covered services may be excluded

from coverage if, 1) it would not be covered as an inpatient hospital service if furnished to a hospital patient, or 2) it is provided to an individual who is experiencing a temporary loss or reduction of function that is expected to improve without treatment, or 3) it is part of a maintenance program of repetitive activities that do not require the skilled services of nurses or therapists.

The special problems of black children

A new book **Black Children: Their Roots, Culture and Learning Styles**, has been released by Brigham Young Press of Provo, Utah.

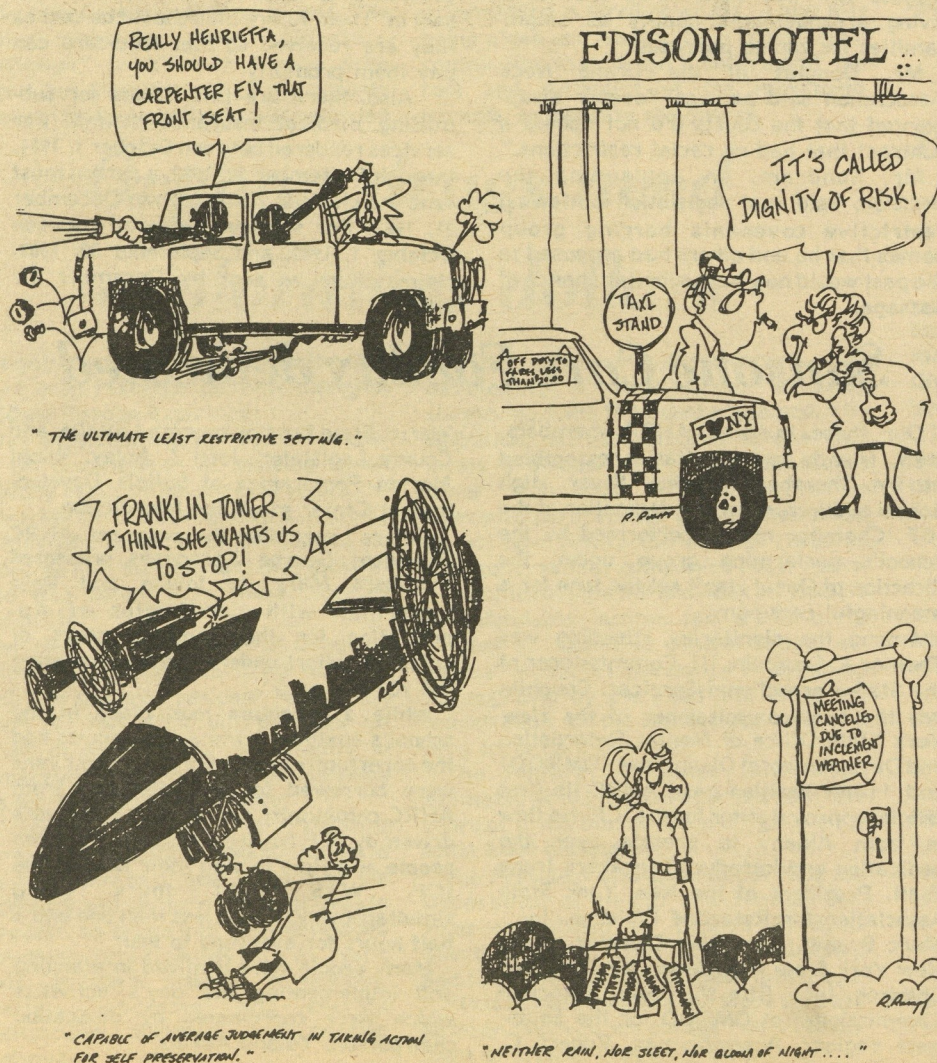
The hypothesis of this book is that Black children grow up in a distinct culture. Black children therefore need an educational system that recognizes their strengths, their abilities, and their culture and that incorporates them into the learning process.

The author, Janice L. Hale, Ph.D., is currently an associate professor in early childhood education at Jackson State University in Jackson, Mississippi. A Black educator, her extensive research reveals the fact that the American educational system has not been effective in educating Black children. "The emphasis of traditional education," claims Hale, "has been upon molding and shaping black children so they can fit into an educational process designed for Anglo-Saxon middle-class children. We know that system is not working."

In reviewing its contents Dr. Edward Zigler of Yale University said, "This book provides a rich conceptual framework within which educators and social scientists can examine afresh their ideas about the development of the Afro-American child."

Janice Hale has made such a clear and compelling case for focusing on the cultural background of Black children that it can't help having an enormous impact on our educational priorities."

This volume offers a new approach for conceptualizing the behavioral pattern of Black children. The author suggests that educational settings be changed to accommodate the learning styles of Black children and to reinforce the strengths of their families.



Help for SSDI recipients

The Senate Finance Committee passed a bill by voice vote on September 28 which would enable terminated disability recipients to continue to receive funding until appeals can be made through the Administrative Law Judge hearing stage.

Although recipients of Supplemental Security Income currently may continue to receive payments while appealing a decision that their disability has improved, Social Security Disability Insurance recipients' payments cease with the termination notice. The bill, S. 2942, introduced by Senator Bill Armstrong (R-CO) which was passed by the Senate Finance Committee will permit the continuation of payments through the ALJ hearing, but requires repayment of those benefits if the judge upholds the Social Security Administration's decision that the recipient is no longer disabled. Armstrong's bill also directs the Social Security Administration to adjust Continuing Disability Investigation caseloads for states so backlogged that "full, careful and timely" reviews are difficult.

Unfortunately, S. 2942 did not go to the floor of the Senate before the election recess. It should be considered soon after they reconvene on November 29, however. The House will be considering similar legislation in the post-election, lame duck session.

Please contact your members of congress in the Senate and House and urge them to pass legislation to protect disability insurance recipients.

CDIs TO SPREAD

We understand that the Social Security Administration plans to begin reviewing the continuing disability of SSI recipients in the near future. Up to this time, SSI problems have come from denials on initial application rather than through disability review.

If any of your clients receive cessation or denial notices, help them appeal the decision. We understand that one of our member agencies has had a dozen cessations successfully overturned with all beneficiaries now on Social Security rolls.

CONGRESS CORRECTS OVERSIGHT ALL ICF-MR CLIENTS MAY BE RECERTIFIED JUST ONCE A YEAR

A technical correction which appears in the Tax Equity and Fiscal Responsibility Act of 1982 (P.L. 97-248) will permit the recertification of Medicaid clients who live in privately operated intermediate care facilities for the mentally retarded just once a year rather than every 60 days.

Last year Congress intended to pass such legislation but the language of the amendment inadvertently limited annual recertification to clients of publicly operated facilities only. A statutory change was required before people living in privately operated facilities could be recertified just annually.

As the result of the recent amendment, Medicaid recipients who live in any ICF-MR may now be recertified just once a year rather than every 60 days. The new law is retroactive to the implementation of last year's amendment, to October 1, 1981.

Licence named Board president

Edward B. Licence — Past President of Nassau County Chapter and a member of the State Board of Governors, was elected President of the Board of Visitors of Suffolk Developmental Center at the December Meeting of the Board.



Calling plays for the Yankees is Phil Rizzuto's bread and butter, but it is not all he does with his time.

As a player, Phil Rizzuto was known for his good glove in the field and good stock at the plate and while calling the plays for the Yankees doesn't provide many opportunities to go to bat anymore, Mr. Rizzuto still wields a heavy stick when going to bat for good causes. Mr. Rizzuto made an appearance at WR Furniture and Rug Liquidators, Hudson, N.Y. in November for the benefit of Columbia County Association for Retarded Children. Proceeds from the day's events including a bake sale, sale of Yankee merchandise and a portion of furniture sales went to contribute to the quality of COARC programs in austere times.

Court lifts ban on group home

RESTRICTIONS IN AN AREA IN SUFFOLK ARE BARRED by Ronald Smothers

A New York State appeals court ruled recently that restrictions written into deeds in a Suffolk County community could not be used to prevent the state from establishing a group home for eight mentally retarded adults there.

The court, a four-judge panel of the Appellate Division, sitting in Brooklyn, reversed a lower court decision and unanimously ruled that such covenants between the buyer and seller of property violated the state's public policy of promoting the "least restrictive" environment for the mentally disabled.

The community involved is the Crane Neck area, an 85-family enclave developed in 1945 in the Village of Oldfield, on the North Shore. Its homes all require a minimum-lot size of two acres and sell for around \$150,000, according to Arthur Douglas, the president of the Crane Neck Association, which originally brought suit in the case.

The Association was suing the state's New York - Long Island County Service Group.

HOME HAS OPERATED SINCE 1980

The group home, which has been in operation since 1980, sits on a wooded tract a quarter of a mile from Long Island Sound.

Clarence Sundram, chairman of the State Commission on Quality of Care for the Mentally Disabled, said that in its ruling the court was putting housing discrimination based on mental disability on the same footing as housing discrimination based on race or sex.

The commission monitors facilities for the mentally disabled.

Kevin A. Seaman, a lawyer for the Crane Neck Association, said he would urge an appeal. He said the decision conflicted with an Appellate Division ruling in the Sputen Duyvil section of the Bronx in 1979. In that case, the legality of a restrictive covenant among the residents of a community was upheld.

UNILATERAL BARRIER OPPOSED

Justice, Richard A. Brown wrote in the panel's decision that "communities and

residents should not be permitted to decide unilaterally by means of restrictive covenants, possibly employing language more specific, that they will not permit the establishment of group residences in their area."

Justice Brown wrote that the 1945 covenant's goal of "preservation of the quality of life and character" though a restriction to single-family dwellings alone would not be frustrated by a group of mentally retarded residents and staff that intended to function like a "family."

State law has determined that such living arrangements qualify as single-families for zoning purposes.

Mr. Douglas of the Crane Neck Association said he was "deeply disappointed that the courts did not uphold a contract that had no racial restrictions."

Mr. Sundram, in applauding the decision, said that legislation outlawing restrictive covenants barring group homes that he and others had proposed in the past would now have a better chance of passage.

Sansone Care Facility dedicated

Our three hundred AHRC members, staff, friends and dignitaries assembled at the Shoreham Wading River High School auditorium for the dedication of the ICF. Chamber music, performed by the school's performing group under the direction of Donal Hanft set the tone for a meaningful ceremony.

Among the dignitaries attending was Thomas A. Coughlin, III, Commissioner of the State Correctional Services. Coughlin was the first commissioner of the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) and, in this position gave AHRC its first official approval letter for the ICF. He flew in from Albany to preside over the dedication and introduced speakers Irene Platt, President of the New York State Association for Retarded Children, Inc.; Marc Brandt, Executive Director of the New York State Association for Retarded Children, Inc.; Elin M. Howe, Associate Commissioner of OMRDD for the Southwest region; Assemblyman Robert C.

For faster claim processing

There are a number of guidelines people should follow to insure that their claims under Medicare's medical insurance are processed as quickly as possible. Most of these tips are covered in a leaflet called **How To Complete the Patient's Request for Medicare Payment**, available at any Social Security Office.

The most common mistakes that result in delays are made in completing the Patient's Request for Medicare Payment form - Form 1490s. Missing information or not enough information on a claim can cause delays. The mishaps may include:

—Failure to sign the claim form.

—Failure to include the claim number. It should be copied from the Medicare card (include the letter at the end of the number).

—Failure to send to the correct address. There's a list of organizations in the booklet, Your Medicare Handbook, that shows which one services Medicare medical insurance claims for particular geographical areas.

—Failure to itemize bills. Each bill submitted must show the date and place the services or supplies were received, the description of each service, the charge for each service or supply, and the doctor or suppliers name. In addition, it is a good idea to check in advance to see whether a doctor or supplier will accept assignment of the bill before accepting treatment or services. This means that the doctor or supplier will accept the responsibility for obtaining payment from Medicare. Medicare pays the doctor or supplier 80 percent of the approved charge, after subtracting any part of the \$75 deductible the patient has not met. The beneficiary is responsible for the remaining 20 percent of the approved charge and any part of the \$75 medical insurance deductible he or she hasn't met.

Don't "bunch" or hold on to bills in hopes of reducing paperwork or expediting payment by sending them all at one time. A person increases the chances of making a mistake and increases the possibility of affecting the flow of Medicare claims, which could affect the speed with which his or her claims are processed. As soon as covered bills come to \$75, they should be sent in. Then, future bills should be sent as they are received so that Medicare can pay them promptly.

Also, there are time limits for submitting medical insurance claims. For services rendered between October 1, 1981, through September 30, 1982, a person must send the claim in no later than December 31, 1983. For services rendered between October 1, 1982, and September 30, 1983, claims must be sent by December 31, 1984.

Wertz; State Senator Kenneth LaValle, and County Legislator, John J. Foley. Rabbi Morton Pomerantz of Suffolk Developmental Center made the benediction.

Before concluding the program, AHRC President George Karadenes presented members Mary Jo Iovino and Rose Silverman with Certificates of Appreciation for their endless hours of volunteer effort undertaken in decorating the ICF.

While a reception took place in the school's auxiliary gymnasium, guests had the opportunity to tour the ICF. Eight vans were borrowed for the afternoon from AHRC community residences. They were driven by ICF houseparents who took ten people at a time to visit their wing of the ICF. With eight tours going simultaneously, it took less than one and a half hours for everyone to visit.

Many people were involved in planning and implementing the day's activities which were coordinated by dedication chairperson, Yolanda Adkins.

Compassionate Friends, Inc.

warn professionals

REMEMBER: AS YOU TREAT THE PATIENT IN THE BED, YOU MUST BE CAREFUL NOT TO CREATE PATIENTS AROUND THE BED!

A pamphlet dealing in depth with what professionals can do to assist parents who may be watching their child die has been published by The Compassionate Friends, Inc. It is reprinted here with their permission.

SUGGESTIONS FOR DOCTORS AND NURSES

Prepare parents and siblings for what they will see before they see it. Explain beforehand the machines, tubes, needles, etc. clean and bandage all you can before they come in.

If parents really want to watch, let them see what you are doing with their child. Let them lead in that decision. (They don't see the same things you see.)

Anticipate their questions as much as possible. Avoid complicated terminology, but don't "talk down" to families either.

ALWAYS TELL THE TRUTH! Tell them everything you know about their child's condition. Be honest about what you don't know. Tell them the numbers, i.e., blood pressure, temperature, pulse, etc.

Let parents "parent" — they need to participate in the care of their sick child as much as possible. Later they need to be able to say, "I helped!"

Give parents permission to talk about their feelings, to be extremely tired, to CRY. Cry with them if you are truly sad. Don't hide your feelings to protect them. You are in a position of authority and your permission (and modeling) give their feelings validity.

Parents may not be accepting of bad news, and may cope by denial. Do be patient with parents as denial is a form of emotional protection and will disappear when an individual is ready. Everyone is on a different timetable. Recognize that sometimes there is a need to repeat the same explanation or information several different times; parents in stress may only have absorbed a little of what you thought had been explained to them.

Reassure families that everything possible is being done. They won't automatically know or assume that. Keep on reassuring them that no measure will be left untried in the attempt to save their child's life.

Take pictures of newborns who die and put them in the file in case parents want them in future weeks or months. (Many will.)

Make EVERY EFFORT to arrange for parents to be with the child at the moment of death if they want to be there. Please don't "protect" parents from this opportunity. It will be extremely important in their later healing.

Refer to the child by name — especially after death.

Remember the two things which concern parents most: "Was my child in pain?" and "Was my child afraid?" Be prepared to reassure as honestly as possible about these questions.

Treat parents equally in giving information and breaking news. Fathers need as much support as mothers.

Families judge you by your caring levels, as well as your medical skills. Convince them their child is special to you, that this is not "just a job."

Allow parents as much time as they need to be with their child (alone if they want) after death. This is vital in their healing process.

At the time of informing parents that their child has died, tell them what steps to take next. They are in shock (and

disbelief) and will be confused and need direction and guidance. There is no such thing as an "expected death" when it happens!

Express your personal frustration: "We try so hard, but sometimes nothing works." "He was such a wonderful child. It hurts us, too, that we couldn't save him."

Touching is our most basic form of comfort and communication — put your hand on the parent's arm, or your arm around the parent's shoulder.

If possible, go to the visitation or funeral. It means more than you can imagine. Families will really appreciate your showing your caring!

Most of the parents we've talked with have appreciated being asked about organ transplants. Parents who weren't asked felt left out or even insulted. However, parents need reassurance that their child's body will be treated with respect and dignity.

Don't expect the parents of a dying child to be logical or objective. Runaway emotions have left logic at the starting gate, and it will take quite a while to catch up!

Don't "hit and run." If you must break sad news, don't rush away immediately. If you can't handle the situation sensitively, send or take along someone who can . . . Don't assume all danger is "displaced." Some of it is, but some is justified and needs to be ventilated and examined.

Don't try to give parents rationalizations about their child's death, such as: "Your child would have been a burden to you as he was," or "She just would have suffered if she had lived." (This is the "You're really lucky he died" routines.)

Don't say, "You ought to be feeling better by now," or anything else which implies a judgment about their feelings.

Don't point out that they can always have another child, or suggest that they should be grateful for their other children. Children are not interchangeable — they cannot replace each other.

Don't suggest "busy work" as grief therapy. Bereaved people know they need to have something to do, but they are extraordinarily tired for a long time, and whatever they do needs to have meaning and importance.

Don't be in a hurry to offer medication. There is a big difference between profound sadness and true depression. Sad people are often medicated for depression unnecessarily!

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Dying...trauma or easement?

by Kate Klein

An enormous interest in the mechanics of biological death and the emotional impact on the family of the death of a child or adult who is mentally retarded has been the focus of parent and professional dialogue this year.

NYSARC has dealt with the impact of parent death on the mentally retarded who out live their parents-caretakers. Through retardate trusts, counseling on wills and guardianship expertise, NYSARC has cautioned and enlightened parents on how to provide for their children.

Another serious aspect is now seen as a need — that of preparing the mentally retarded for the death of a parent or any member of the family. Acceptance of death is a life lesson which can be brutal or natural according to the preparation, parents have learned.

Because the finality of death is always a jolt into reality it is regarded as a magnified loss to a child or adult who is mentally retarded, particularly those who have always lived at home.

SURVIVORS NEED HELP

An organization totally concerned with the impact of death on parents who survive a child is Compassionate Friends, Inc., with national headquarters in Oakville, Illinois. It has local groups of parents who meet regularly and discuss how they coped with grief, or were not able to cope. The association is a support group of parents and family members who have experienced the trauma of the death of a child. Their conversations and sharing of experiences and feelings in regular sessions have become a satisfying way to meet the needs of parents who must understand the process of bereavement. They learn the importance of having conversation about their own feelings and about the child who has died and that child's contribution to the family.

NYSARC ASPECTS

Renowned Louis Bascaglia, Special Education expert who lectures on the importance of love and loving has opined in his textbook on counseling of parents of the handicapped that when a child who is handicapped is born into a family, those parents should experience a kind of mourning of the death of parenting expectations (mourning of the child they hoped to have who was not handicapped). It often happens without realization that it is happening. When experienced and then finished as one of the steps in facing the special parenting responsibilities for the handicapped child it assists the members of the family in their new adventure in family life built around the considerations necessary for the care and family interaction (love) with the handicapped infant.

STAFF AND PROVIDER'S GRIEF

Recently Warren-Washington Chapter developed a training course for staff on Death and Dying. After the death of a

resident, staff which has cared for the mentally retarded adult often for many years in a day to day relationship has to face the process of grief. The session included legal and practical considerations in preparing for the eventual death of a client. Presenter was attorney, Michael Muller. Also emotional concerns in dealing with personal grief felt by staff members and family members were discussed by a psychologist, Steve Smoller. "Staff must do receptive listening to members of the family," Smoller said. He identified the grieving state of mind as "emotionally flooded," according to Betty Pender who attended the conference. Religious, moral and family concerns in dealing with death and dying were developed by Betty Pender, as presenter, who insisted that no matter how uninvolved the parent was in the life of the client, staff had an obligation to show the proper degree of concern and feeling, apart from their own concern and feeling as a person whose life touched importantly on the client's daily life.

Rev. Robert Powhite spoke on the religious aspects of dealing with grief. Questions were raised on the techniques of leaving a body to science, donors wishes and religious aspects of donating. Betty Pender, Chairperson of the Education Committee said that workshop was one of the most exciting workshops she had ever attended. "Death and dying are touchy subjects" she said, "and dealing with the wishes of a deceased client with regard to funeral arrangements when they are not consistent with the wishes of the family can be very divisive."

Discussion was generated on specific issues like — How should staff deal with over-protective parents who won't allow a son or daughter to help make the necessary arrangements regarding their eventual death? Should staff members share their grief with the family members over the loss of one of the clients or does staff have the responsibility to be "Strong" and help the family in their grief? These important sessions were video-taped. Other chapters may want to review them as an assist to an important life-training aspect for parents.

PARENTS NEEDS

We queried various members casually on these subjects to get a feeling about what might be included in an article on death, dying, bereavement, and survivors emotions. One letter, from a sensitive, experienced parent who prefers to be unidentified at this time, sums up a reaction to this crucial need.

"Unfortunately, although our love for our child who is retarded is no less than that for our other children — and sometimes it is even greater — there is a different feeling when that life is at an end", she wrote.

"Kate, in my years association with parents of retarded children, it has been my unhappy duty to try to comfort some of them at the time of death of their child. Never once have I met one who was not relieved that the child did not survive them.

It is our love that sustains the child and ourselves, sometimes to the detriment of our relationships with our other children. To pass the responsibility to them is unfair . . . General Charles DeGaulle and his wife had a retarded daughter. Mrs. DeGaulle spent much of her life devoted to the mentally retarded in France, even to her seeming withdrawal from society . . . resentment and perhaps a sense of guilt can do that.

Anyway, when the daughter died — the General said to his wife, "Now she is just like all the other children." I think that says it all — and I do repeat it whenever the unhappy occasion presents itself."

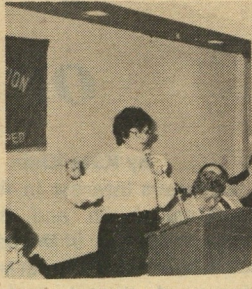
Being retarded
never stopped
anyone from
being a good
neighbor.



Board of Governors Meet



Board of Governors Representatives studying material prior to voting.



Irene Platt, President, listening to responses



Marc Brandt, center, speaks to Governors surrounded by, from left, Bernie Volaski, Southeast Vice President; Irene Platt, President; Shirley Reynolds, Secretary; David Lettman, Western Vice President.

Tourette Syndrome in mentally retarded children

By Gerald S. Golden and Lawrence Greenhill

Abstract: Tourette Syndrome, a condition beginning in childhood, is characterized by both chronic motor and vocal tics. Bizarre stereotyped movements, compulsive behavior, and coprolalia are often present. In this study, six mentally retarded individuals originally manifesting these symptoms are first thought to have manneristic behavior. Prompt response to treatment with haloperidol exposes their true nature as tics associated with Tourette Syndrome.

Tourette syndrome is being reported with increasing frequency in both children and adults (Shapiro, Shapiro, Brunn and Sweet, 1978). This apparent increase in incidence is a function of clarification of acceptable diagnostic criteria and much publicity, largely through the efforts of the Tourette Syndrome Association. The importance of this heightened awareness is evident: 85 percent of all cases are still initially diagnosed correctly by the patient or a member of the family, with an average delay from onset to diagnosis of four years.

The Syndrome starts in childhood and the cardinal feature is a changing repertory of motor and vocal tics (Golden, 1976). The motor tics may be, initially indistinguishable from simple childhood tics and most frequently include eye blinking, head movements, and facial grimacing. The arms are involved less frequently; legs even more rarely.

Vocal tics include throat clearing, sniffing and coughing, as well as other inarticulate sounds. Loud and bizarre cries and screams may occur and some patients make sounds such as barking or crowing. The involuntary utterance of words or short phrases sometimes occurs.

Complex stereotyped movements may be part of the symptom complex, as well as: compulsive touching of self, others, or objects; compulsive chewing of objects; and, compulsive sniffing. Coprolalia, copropraxia, echolalia, and exopropria are not among the mandatory diagnostic criteria, although if present are helpful in

early recognition of the syndrome. The repertory of symptoms changes with time and severity waxes and wanes even without therapy (Sweet, Bruun, Shapiro and Shapiro, 1976).

MANNERISTIC BEHAVIOR

Mentally retarded individuals often manifest behavior which is manneristic. Complex stereotyped movements, compulsive activities, and unusual vocalizations may be seen. These are troublesome symptoms, as the ultimate adjustment of a mentally retarded individual depends on social acceptability and competence. These phenomena produce a behavioral stigmatization which, in the minds of many individuals, identifies the person as being either mentally retarded or mentally ill.

This report concerns six children who are mentally retarded and have abnormal vocalizations and motor tics. Their symptoms fit all of the diagnostic features of Tourette Syndrome and treatment produced favorable results in four of the five children for whom therapy was begun. Although the vast majority of patients with Tourette Syndrome have normal intelligence, the recognition of this condition in mentally retarded individuals and application of effective treatment can reduce the social incapacitation in this already stigmatized group.

The diagnosis of Tourette Syndrome, often made following long delays and visits to many physicians, may be confounded when appearing in a mentally retarded individual. The presence of manneristic behavior in mentally retarded individuals is frequent and generally does not represent this condition. The diagnostic criteria as outlined are straight-forward, and if present are highly predictive of a beneficial response to a particular class of pharmacologic agents, the butyrophenones. Treatment may benefit a meliorate socially disruptive behavior. It must be approached cautiously, however, because of the high incidence of extrapyramidal reactions in these patients.

Doctors attempt to block federal infant life rule

The National Associations of Pediatricians and Children's Hospitals have sued Secretary of Health and Human Services Margaret M. Heckler to block implementation of a new federal rule aimed at preventing doctors from letting handicapped newborn children die.

The suit alleges that the government did not allow proper time to comment on the rule, scheduled to take effect March 22, only 15 days after it was first proposed.

The suit was filed March 18 in U.S. District Court for the District of Columbia by the American Academy of Pediatrics, representing 14,000 pediatricians; the National Association of Children's Hospitals and Related Institutions; and Children's Hospital National Medical Center in Washington.

At a news conference on the day the suit was filed, Dr. James Strain, president of the Pediatrics Academy, said the "regulation would inject federal investigators into the pediatrics wards of this country in a way that is dangerous to the health and lives of seriously ill infants."

Medical groups and the government share the same goal, "to protect the lives of all children, including handicapped children," Strain said, but he argued that ethical review groups in institutions are the proper overseers of decisions to withhold food and treatment from infants born with defects.

The National Right to Life Committee has supported the Department of Health and President Ronald Reagan has endorsed it. Surgeon General C. Everett Koop defended the new regulation as necessary "to save the lives of children in jeopardy."

Koop, formerly a Philadelphia pediatric surgeon, said, "The rule does not require prolonging the act of dying, but, rather, protecting the act of living through appropriate nourishment and care." He said it would not have affected the way he practiced medicine.

Dr. John C. Wilke, president of the

National Right to Life Committee, took a similar position.

The rule would require hospitals to post federal notices in delivery and nursery units that failure to feed and treat handicapped infants is against the law. It would also set up a special telephone hotline for calling in complaints. Violations could lead to denial of federal funds to the hospital involved.

The regulation elaborates on a warning issued by the government last spring after a baby died in Bloomington, Ind., when his parents, backed by their physician and the courts, allowed food and treatment to be withheld. The child was born with Down's syndrome, which leads to mental retardation, and respiratory and digestive problems requiring major surgery.

In addition to filing the suit, the Pediatrics Academy and 12 health groups wrote to Mrs. Heckler to protest that the rule was issued without the normal 60-day period for public comment. The American Medical Association sent a similar protest.

The Department of Health and Human Services said the emergency procedure used in issuing the regulation was warranted "to protect life from imminent harm."

REAGAN ADMINISTRATION TO APPEAL COURT RULING

Judge Gershon A. Gesell, a Federal district judge struck down in April a new rule requiring 6,400 hospitals in the United States to provide food and medical care to infants born with severe mental or physical defects.

Judge Gesell said the rule issued by the Reagan administration in March was "arbitrary and capricious". Further he said it was adopted in violation of the Administrative Procedure Act which requires government agencies to give the public an opportunity to comment on most rules.

The Reagan administration announced immediately that it would appeal the ruling.

Developmental Disabilities Resource Center opens

Duncan Whiteside and Mariette Bates have opened a Resource Center for Developmental Disabilities, located at 30 East 29th Street in New York City. The Center offers a range of services to parents, professionals and advocates in the field, including information and referrals, training programs in management, grantsmanship, program development and community acceptance, and help for agencies on fundraising and public education projects.

Projects currently underway at the Center are varied. Staff are working with several different groups to secure services for deaf-blind young adults who will be graduating from their educational programs in the next few years and will need residential and day programs. Another project involves researching and developing a network of services for high-functioning young adults with learning disabilities, who need minimal supervision but cannot make it on their own. In addition, the Center is assisting several agencies in designing individual funding plans based on the needs of each agency.

The Center's funding comes from a

variety of sources. Foundation and corporate grants cover the cost of the information and referral service. Training programs are budgeted to cover the cost of Center staff and training materials. Agency consultations will be charged at significantly lower rates than profit-making consultation would normally cost, to allow agencies to afford this service.

Mr. Whiteside and Ms. Bates have worked together for the past five years. Mr. Whiteside, formerly the Director of One to One, has been an active advocate in the field of developmental disabilities, mental health and juvenile justice for the past ten years, after leaving a successful career in international banking. Ms. Bates, who worked as the Director of Training at One to One, has been an advocate for the mentally disabled for the past eight years.

The Center, which is based at the Mental Health Materials Center, can be reached by calling (212) 581-0784, or by writing the Resource Center for Developmental Disabilities, 30 East 29th St., New York, N.Y. 10016.

Preparation for Parenting

Adopting the special needs child

From:

Family Life Development Center

As parents learn more about themselves, they also learn about the children available for adoption. In Tompkins County, New York, applicants learn about different forms of mental retardation or physical handicaps, visit the community's Special Children's Center to see first-hand the effects of these handicaps, and meet other families who have adopted special children. They begin studying exchange books that describe waiting children.

In the early 1970's, the typical child available for adoption was not the stereotyped white infant, perfect and cuddly, but an older child, often with emotional problems or mental and social disabilities. Because of the inevitable stresses new families face, Tressler - Lutheran Services Associates (T-LSA), a multiservice agency in central Pennsylvania, realized that it had to provide both the adoptive parent and the child with special assistance.

In planning an assistance program, T-LSA drew on its experience in establishing parent education and communication skills training for biological families. It tailored that program to the family that was adopting an older, special-needs child. These children may have one or more of the following characteristics: they are over the age of 10, mentally retarded, physically or emotionally handicapped, one of several siblings also available for adoption, and of a minority group.

T-LSA conducts an educational home study that embarks applicant parents on a path of self-discovery and informed parenting. They are allowed to be partners with the agency in choosing a child. This approach has been replicated in many communities. Group training sessions are led by agency staff and adoptive parents, who share their experiences and serve as an on-going support system.

When applying to adopt a child, prospective parents are asked to complete an autobiography. This statement and other materials about the applicants are sent to child - placement agencies. This

body of material, called the home study summary, is an attempt to convey the family's life-style and personality to agency personnel so that children can be matched with the homes most suitable for them. A family does not have to meet specific criteria. Adoption workers recognize that just as children's needs differ, homes differ, too.

As one adoptive parent said, "Commitment to the child is a must, come what may. Sometimes it's enjoyable and sometimes it's not, but in adopting these children one remains committed, even during the times when it's not so enjoyable."

HOME IS WHERE THE CARE IS

A training series of nine weekly sessions for prospective parents conducted jointly by the agency and seasoned adoptive parents includes various self - discovery activities.

Jean Teltelbaum, adoptive parent and trainer for part of the group home study in Tompkins County, New York, lists four major themes that govern planning of the self-discovery approach:

1. The necessity of parents having information about special - needs adoption to permit appropriate family self - assessment.

2. The necessity of commitment in adoption.

3. The necessity of support in special-needs adoption and the appropriate resources for that support.

4. The necessity of developing parenting skills and knowledge of child development.

"These four themes are developed throughout the group meeting by use of direct presentation of information, group discussion, exercises, handouts, and homework," say Jean. "Each presentation, discussion, or exercise is designed to develop a commitment to special - needs adoption and to enhance understanding of children in the foster care system, the demands they may make on a family, and some of the basic skills a parent can use to handle behaviors positively."

"504" complaints on rise

The types of civil rights complaints received in the Department of Education (ED) and the Department of Health and Human Services (HHS) have shifted dramatically in the last several years, according to the Civil Rights Forum, Vol. 6, No. 1, Fall 1982, a publication of the U.S. Department of Justice, Civil Rights Division.

During the 1976-78 fiscal years, the largest number of complaints that HEW received alleged violations of Title VI of the Civil Rights Act of 1964 (based on race, color, or national origin). Beginning with FY 1979, over 30 percent of complaints filed with HEW involved Section 504 of the Rehabilitation Act of 1973 (discrimination based on handicap). By FY 1981, over 50 percent of the caseloads of HHS and ED involved 504 complaints.

The majority of the Section 504 complaints received by ED are against elementary and secondary schools. In FY1980, 1,124 of the 1,449 Section 504 complaints (78 percent) were against such schools, and in FY 1981, 1,059 of the 1,436 Section 504 complaints (74 percent) were filed against the schools.

While there has been an increase in the number of Section 504 complaints filed, there has been a decline in complaints involving Title VI and also Title IX of the Education Amendments of 1972 (alleging violations based on sex). In FY 1979, Title

VI and Title IX complaints accounted for 48 percent of ED's workload. This declined to 38 percent in FY 1980, to 36 percent in FY 1981, and to 30 percent for the first time three quarters of FY 1982. During that part of FY 1982, ED received 674 Section 504 complaints.

HHS has also experienced a drop in Title VI and Title IX complaints receipts. Sixty-five percent of all complaints filed with HHS involved health facilities, 25 percent involved human services, and 10 percent involve other services. During the first six months of FY 1982, HHS received 206 Section 504 complaints.

Could this ad have been written ten years ago?

ROOM RATES: MEXICO

The Gran Hotel Victoria has 140 rooms, all singles or doubles with private baths. The doubles face on the plaza. Prices start at 2,000 pesetas or about \$16 for a single, about \$27 for a double and about \$39 for rooms 330 and 408. These rooms each have two beds; 330 also has two Murphy beds.

The hotel has a restaurant, bar, room service and elevator. There is one step up to the entrance, four steps up to the elevator and **NO RAMPS FOR WHEELCHAIR ACCESS.**



Talking Money

Bob Meltzer, Co-Chairman Budget and Finance with Anne McDonnell, Asst. Treasurer, NYSARC, Elliot Aronin, Co-Chairman — Budget and Finance, Bill Safee, Member of Budget and Finance Committee.

ARC clients learn joy of accomplishment

By James Kinsella

PLATTSBURGH — Pat Kindle briskly walked up Tuesday evening to a man in the lobby of Clinton Community College, shook his hand, and asked him "Can you tie a tie?"

When the man said yes, Kindle handed him a necktie, took off a checkered sport-coat, turned up his collar, and waited for the deed to be done.

Kindle spoke amid a excited hubbub that might proceed a college graduation. Indeed, he, along with 16 other clients of the Association for Retarded Children, was about to receive a diploma in the "College for Living" at the community college.

The ARC clients had completed four-week courses in either first aid or sewing. Their teachers were five Clinton students majoring in human services: Tammy Ashline, Carol Ashline, Cheryl Jacobs, Holly Jolicoeur and Vicki Tolosky.

In 1981, ARC Executive Director Phil Hoffer first suggested that Clinton offer courses to association clients. These courses, in turn, have been directed by Adela Bekerman, an assistant professor community services and sociology at the college.

Sixty-one people crowded into a third - floor classroom for the graduation ceremony. Besides the graduates, their teachers and Bekerman, those on hand included friends, family and fellow ARC clients, as well as Clinton Academic Dean John Garmon.

Following presentation of the diplomas to the clients, who ranged in age from the 20s to the 50s, several graduates pinned buttons showing a heart and "VIP" (for Very Irresistible Person) on the student teachers and Bekerman. A client then posed the question of the hour.

"What time is the party?" he asked.

Immediately thereafter in the fifth-floor faculty room was the answer. That's where the clients and their guests headed. They ate cake, drank punch and munched snacks under colored balloons, each marked with a graduate's first name.

Graduates in the sewing course were Kim LaForest, Jona Pope, Lucy LaFountain, Robert Hart, Anna Barcomb, Billy Martin, Kindle, Cynthia Scrodin, Cathy Rock and Francis McCort.

Clients who received first-aid diplomas,

were Brenda Hicks, George Dilorenza, Don Gougeon, John Watson, George Mills, Martin Wasmuth and Cliff Connors. Steve Skarsten, Elaine Coffin and Mike O'Neil also graduated from the first - aid course but were unable to attend.

Beckerman said the clients in the sewing course learned basic techniques and made pillows. Those in the first-aid course again learned basic information and practiced on each other.

Some of the clients had taken previous College for Living courses at the college. Sessions were offered the past two summers. Among these clients was Gougeon, who had taken dancing during the last session.

"I like it," said Gougeon, a handsome, earnest man. "I worked hard on my first aid. It's something I can learn by and I hope I can come back next year to do it again."

The Clinton student said they enjoyed teaching the courses. Four of them previously have taught the courses; Jolicoeur is the newcomer.

"I love the people," said the woman, who had brought along her husband and two children to the ceremony. "They're very honest and very open with their feelings. They're up; they're happy all the time. They're huggers."

Her last observation was demonstrated by Kindle, who hugged a photographer after posing with Jolicoeur and his diploma.

Michael Conine, the ARC assistant executive director who was on hand for the graduation, said the courses satisfy the goals of the association and the needs of the clients.

"We want (the) people to come out in the community, and this is a way of doing it," Conine said.

A bit later, in the kitchen to the side of the room, Gougeon hugged Tolosky, his teacher.

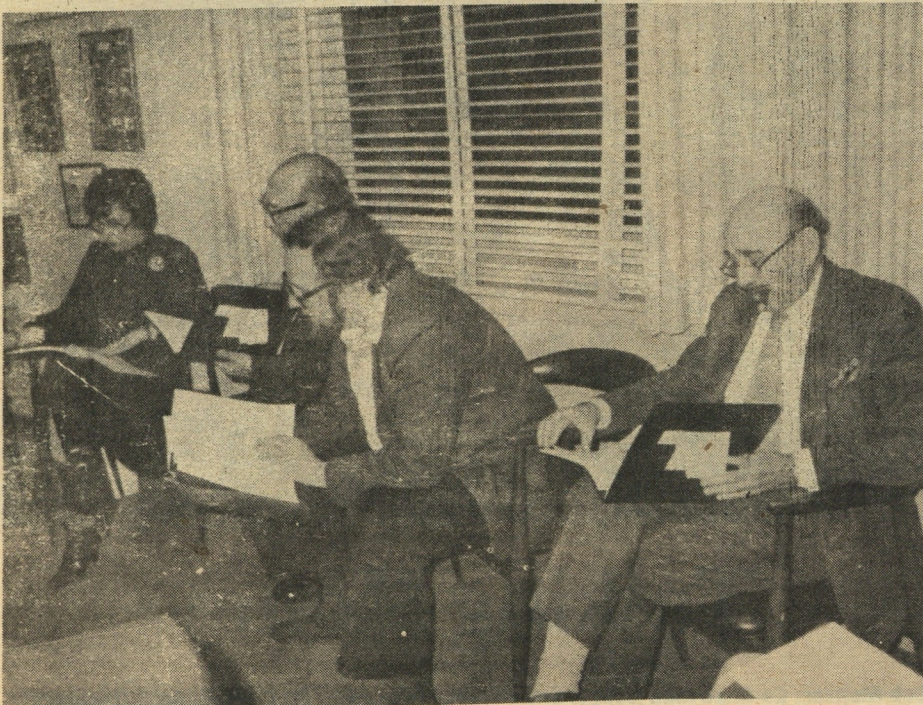
"I going to miss you," he told her.

"I'm going to miss you too," she said.

After he left, Tolosky reflected on her students and the College for Living. "It's a lot more caring," she said. "They appreciate things a lot more than anyone else would."

(Press from the Republican)

Property Acquisition



BEFORE

President, Irene Platt, with Seymour Robin, Michael Goldfarb and Joseph T. Weingold of the Budget & Finance Committee.



DURING

NYSARC Executive, Marc Brandt, answers questions while Elliot Aronin, Chairman - Budget & Finance Committee, Ellie Pattison, Regina Black, Executive Committee, study proposal.



AFTER

Bob Meltzer Co-Chairman, Budget & Finance Committee surrounded by Ellie Pattison, and Irene Platt, Executive Committee and Ann McDonnell, Asst. Treasurer, NYSARC.

Watch your language!

Dear Editor:

I read with great interest Ms. Smolen's letter in Forum on the habit of referring to people who are mentally retarded as clients.

Here are two letters on this subject. I think it is so important that we watch our language. Instead of saying mentally retarded persons — say persons who are mentally retarded.

Betty Pendler

Gentlemen:

I received a good many of your publications relating to persons who are mentally retarded, and I am delighted with the wonderful work your Committee is doing in helping to raise public consciousness, and change the image that the public has in general of persons who are disabled.

However, I would like to give you a grammar lesson if I may be so bold, and urge that all your future writing make sure you use the "predicate nominative" when speaking of persons who are disabled. This little gimmick of consciousness raising places the positive word "persons" first, which hits the mind, then comes the disabled. We all emphasize that the public should look at the "abilities" of people who are handicapped; we urge the public that although some people who are handicapped may be different, not to let the differences make any differences; yet we, ourselves, fall into the trap of using the negative word first.

I am writing this because I have become almost fanatic on this issue, since both as a parent of a daughter — who is retarded — and who is active in this area, doing much public speaking on the subject of attitudes, I have seen this little change work. The women's movement succeeded in getting many people to change words; why can't we. I have had the occasion to address groups for the Head Start Program to teachers who, understandably, are a bit apprehensive in the beginning about bringing in children who are handicapped to their program.

In the course of my talks in the training

session, I bring out this grammar lesson and urge the teachers, in describing a new child who is handicapped coming into their class, not to say "tomorrow we will have a blind boy", but rather — "tomorrow you will meet a boy who is blind" so that the immediate image is a boy with pants on — who happens to be blind — and they have reported to me that it works.

I have made a nuisance of myself to my friends and relatives by stopping them and making this correction, and have stopped educators as well, but happily, many of them have picked me up on it, and are now correcting others. May I urge, therefore, that in your future publication — even though it sounds repetitive at first — to please say persons who are handicapped, rather than handicapped persons.

This may be deemed an insignificant suggestion, but I am convinced that it can go a long way as the unconscious mind received the positive word first. Thank you for your consideration to this matter.

Very truly yours,
(Mrs.) Betty Pendler

Dear Mrs. Pendler:

Please excuse the delay in responding to your letter of April 6. I fully understand and concur with our concerns about language usage. In fact, I have heard from one of our mutual associates, Dr. Gunnor Dydwid, who reinforces your interest and concern in this area.

Often there is no excuse or rationale for the types of language that has been used in reference to persons with the condition of mental retardation. In sharing your letter with other members of our staff or committee, they commented that they concur with you, but we have been making considerable progress in this area over the last several years. However, that does not excuse an inappropriate terminology or usage of language. A dignified reference to all people of mental retardation needs to be followed. Thank you for bringing this matter to our attention.

Sincerely,

Fred J. Krause
Executive Director

Cook alone-Dine alone

A COOK BOOK "SPECIAL RECIPES FOR SPECIAL PEOPLE" by David Lurio, illustrated by, Peggy Lopatz and published by Skylight Press, PA, is available for use on gas and electric ranges.

This book was written in the belief that cookery skills are first among the survival skills which a handicapped person must have if that person is to be independent. Its success is in its pictorial step by step instructions.

Cookbooks rely on the reasoning skills and motor skills of the cook but this book was created with illustrations to serve the person with low reading ability.

Simple, nutritious enjoyable meals are included in "Special Recipes for Special People."

Orientation to the kitchen and its varied appliances and utensils is important to the successful completion of each one portion recipes.

In order to use this cookbook successfully, the cook should know how to correctly use knives, stove and oven and all electrical appliances — toaster, mixer, blender, etc. also how to use and set a timer. Understanding how to accurately measure dry and liquid ingredients is another pre-requisite.

In testing the recipes with certain cooks, especially the non-readers, difficulty was found with the proper progression of steps

in a recipe. To solve this problem, markers, such as pieces of paper (or poker chips) can be given to the cook with the instructions that a marker be placed on each step as completed — Eventually as the cook gets used to the progression of the steps in the recipe, the use of markers can be phased out.

Users of the cookbook can look forward to many enjoyable hours in the kitchen!

Write for education manual

"Understanding Your Child's Needs — Parents Lead the Way" is designed to help parents understand how their child's special needs relate to an education program. "Your Child's Right to a Free Appropriate Education" is a resource manual for parents of children with handicapping conditions seeking an active role in planning their child's educational program. These manuals are available for the parents of your chapter for \$3 per copy from the Commission at 99 Washington Avenue, Suite 730, Albany, New York 12210.

Parents get into act; have fun with sun, moon and music

By Kate Klein

Ms. Joan Lengel, a music therapist with an interest in Special Education, became concerned a few years ago when the young adults who are mentally retarded drifted off to television after the music therapy sessions which she knew were so enjoyable for them. There ought to be some way to involve such students in direct music, she thought, but the usual teaching methods for piano are too complicated for teacher and student to use. Why not a piano method for those who can't cope with formal music instruction? — she asked herself and promptly set down to develop such a piano method based on color coding rather than notes.



Joan Lengel, a Yonkers music therapist and author of "I Can Play the Piano".

While teaching music at an Occupation Training Center for the Mentally Retarded she wrote a collection of curriculum songs with rhythm accompaniment set to familiar tunes. The next step was to develop a piano teaching methods book "I Can Play the Piano" for use with individuals and groups by special educators. Even more important, because use of the book requires no prior musical training, it is easily used by parents who want to teach their children at home.

Ms. Lengel believes that parents can become involved in their children's education and when they do it is extremely satisfying to both.

That Parent Frustration — how much practice every day is resolved by Ms. Lengel — Three five minute periods a day is better than one long practice period, she

insists, because the attention span of the student is taken into consideration.

Much success has already been demonstrated for this book with Down's Syndrome children and young adults. The color - picture matching system which uses color coordinated finger rings, block board along with blocks of music, and using the sun and the moon as signals, is easily understood by student and parent. The student quickly learns proper playing position on the piano plus the elements of counting, melody and rhythm through tracing, tapping and singing. Most of the training is learned before the student actually touches the piano keys.

Ms. Lengel is the mother of two, David, eight and a half and Rachel, four. When developing the piano methods book, her husband, also a special education teacher, and David were enormously helpful. David in particular, filled in the color coded stamp areas, a time - consuming process because each student has his own book.

Eventually, Ms. Lengel said, students while not taking part in duets, can play together, in an alternate role. Once learned it is fun to adapt a favorite song to the method.

Presently Ms. Lengel is developing and implementing music program for her method in both the New York City school system and in Westchester. The "I Can Play the Piano" teaching method has been used by teachers, high school student volunteers, parents and by herself in the classroom and the home.

The Public Information Committee has invited Ms. Joan Lengel to demonstrate her piano method at a convention in Lake Placid this Fall.

Simulated Quality of Care

The New York State Commission on Quality of Care for the Mentally Disabled has available for rental two videotapes designed to help parents and professionals become educational advocates for children with handicapping conditions. Also available are two comprehensive resource manuals which cover the basic areas of knowledge relevant to educational advocacy and the necessary skills of an effective educational advocate.

VIDEOTAPE DESCRIPTIONS:

"Parents Speak Out": Advocating for Your Child's Educational Needs"; 12 minutes; conveys, through the discussions of four parent advocates, the message that education advocacy can be a rewarding experience. This videotape introduces experiences and feelings that may be encountered as an educational advocate.

"A Simulated Committee on the Handicapped Meeting"; 25 minutes; and "The Impartial Hearing: A Simulation"; 30½ minutes (both on one tape), depict two important steps a parent advocate or professional can take in securing an appropriate education for a child with a handicapping condition. Through the portrayal of the case of Cindy Bee, the audience will witness Cindy's mother effectively employing advocacy skills and techniques as she first negotiates the dicational placement of her child at a Committee on the Handicapped meeting, and later challenges the Committee on the Handicapped's decision through an impartial hearing. This videotape is appropriate for both beginning and experienced parent advocates and professionals. Contact: Jane Murpey (518) 473-8677. Rental Fee: \$15 - one tape - \$25 - both tapes.



Day Care at Letchworth

"The Thiells Child Center is a True Measurement of What Employers Working with Employees Can Do." Letchworth received \$10,000.00 "Seed Money" from New York State's Committee on Work Environment and Productivity early last year to establish an On-Campus Day Care Center as part of a program to reduce absenteeism and tardiness among staff and to aid in the recruitment of new employees. Letchworth Director, Edward Jennings, local PEP President; Gail Soro, local CSEA President; Bobby Watkins and Council 82's Janie Niedworok, joined together to officially open the Thiells Child Center.

(Photo by Lowell Handler)

Winifred H. Morrison named Erie Executive



Winifred H. Morrison, Executive Director, Erie County Chapter.

WINIFRED H. MORRISON APPOINTED EXECUTIVE DIRECTOR

Winifred H. Morrison has been appointed Executive Director of the Association for Retarded Children, Erie Chapter, Louis J. Billittier Center, 101 Oak Street, Buffalo, New York. Previous to the appointment, Mrs. Morrison was the Agency's Director of Children's Services.

Before joining the ARC, Mrs. Morrison was the Coordinator of the Child Care Advisory Services at SUNY Buffalo where she is currently a lecturer in Health and Human Services. She has developed and implemented courses on issues relating to mental retardation and education. The newly appointed executive is a Doctoral candidate at the University.

Mrs. Morrison holds several degrees in Education and Library Science and numerous New York State certificates in Supervision and Administration.

Winifred H. Morrison is well known in the not-for-profit sector where she has contributed her expertise as consultant for the United States Department of Health; Education and Welfare; Buffalo Public Schools; Catholic Charities; as advisor to local schools and day care organizations; as author of books and articles dealing with education, health, nutrition, and family life. She has held office on Board of Directors of several local and state organizations. Mrs. Morrison has made professional contributions throughout Western New York to civic and social service agencies, local colleges as well as media presentations.

Her current memberships include Pi Lambda Theta — National Educational Honor Society, Center for Women in Management, National Association of Female Executives, Zonta International and other professional organizations. In 1979, Villa Maria College awarded Winifred H. Morrison the Outstanding Service Award, and she is listed in Who's Who in American Women and the International Biographical Dictionary.

As Executive Director of the Association for Retarded Children, Erie Chapter, Mrs. Morrison will direct the programs and services provided to mentally retarded persons by ARC through the Heritage Education Program, Allentown Industries, Community Residence Program, and the Community Planning — Neighborhood Services unit.

The Erie Chapter has been providing services to the retarded for over 30 years. Mrs. Morrison looks forward to working in the new facility, the Louis J. Billittier Center, which will allow ARC to provide expanded services and more job opportunities for retarded persons.

School boards a "business"

Nearly one-fourth of all school board members in New York State list their occupations as business, a new statewide survey shows.

Of the nearly 2,000 school board members responding to questionnaires distributed by the New York State School Boards Association, 23.2 percent, nearly one of every four, said their career field related to business.

The second largest group, 10.3 percent, listed their occupation as elementary, secondary or higher education.

The complete results are compiled in the 1983 Facts and Figures booklet just published.

The booklet also includes enrollment figures, school board size and make up and percentages of males and females.

Also included are the latest salary figures for public school administrators and teachers, plus selected financial data about school districts and pupils and state aid to education.

Copies of the booklet may be obtained for 50 cents each by writing Facts & Figures, YSSBA, 119 Washington Ave., Albany, NY 12210.

CHAPTER NEWS What ou

ALBANY COUNTY CHAPTER — HONORED ITS FOUNDER, Mary L. Caniano by renaming the Center, the Mary L. Caniano Center. Three Board of Directors of the Chapter presented her with a plaque which will be on display at the Center. Edward Lukomski, Executive Director of Albany Chapter was presented with a Certificate of Achievement from the National Industries for the Severely Handicapped (NISH), in recognition of the high standard of performance exhibited throughout 1982 for maintenance services provided by the Chapter's Federal Maintenance Training Program, at the Leo O'Brien Federal Building.

ALLEGANY COUNTY CHAPTER — in our last edition we reported that Allegany netted about \$5,000 on the raffle of a car donated by Family Ford of Wellsville. We have been informed that the Chapter did net \$5,000 but the auto was purchased not donated.

CHAUTAUQUA COUNTY CHAPTER — has begun its second federal contract for the Department of Defense. This contract calls for the production of 2,500 insect bars (mosquito netting) per month. Approximately 15 persons were employed in the initial stage of this contract. Chautauqua's Executive Director, Michael Raymond has been appointed to the Program Services, Research and Prevention Committee of ARCUS. ARC Independent Living Center grants from OVR will enable the Chapter to set up a ILC Program and hire a full time attorney as an in-house advocate and to direct the new center.

CHEMUNG COUNTY CHAPTER — has celebrated its 30th Anniversary Year with a sign dedication ceremony attended by our President and Executive Director — Chemung's first Board President, Mr. Donald Levingier, was named Honorary Chairman. Also on hand were two other original Board Members, Warren Tompkins and Marie Crowley, as well as Chemung County Executive, Robert Devsberger and Elmira Mayor, Mary Pat Ciccariello. Local news media did an excellent job in publicizing the event.



Living Tribute — Louis J. Billittier, left, receives a standing ovation at Dedication of the new home of the Erie County Chapter Association for Retarded Children and Allentown Industries at 101 Oak St. The \$2.2 million facility has been named for Mr. Billittier who has devoted years of service to the retarded and played a key role in raising funds for the center. Among those honoring Mr. Billittier are Mayor Griffin and County Executive Rutkowski, at right. The new building will allow Allentown Industries to increase its capacity from 210 to 300 clients by 1985.

HERKIMER COUNTY CHAPTER — the Rehabilitation Staff of Herkimer Industries is extremely excited about the Vocational Skill Training Program taking place at Mohawk Valley Fabricating, as the competitive employment potential of graduates of the program is exceptional. Individuals participating in the program will acquire blueprint reading skills and become familiar with structural steel and architectural design. The individuals will be trained on commercial welding, commercial metal cutting, and metal preparation as they become deeply familiar with the various commercial tools, equipment, and processes of metal fabrication.

MADISON COUNTY CHAPTER — Madison County ARC Board of Directors sponsored a Staff Appreciation Day at the Rusty Rail with a luncheon. About 76 full time and part time employees were honored. Certificates and pins of appreciation were awarded to 11 who have served the agency continuously for 5 years or more and 3 who served the agency 10 years continuously.

The pins are silver and gold especially designed and hand-crafted for the agency by Al Wardel, Metal Arts Director, Munson Williams Proctor Institute, Utica, N.Y.

Several poems, projections and an ode to the new director of Rehab were presented. A musical comedy skit "spoofing the operations of ARC" was written and directed by a former employee of the agency.

Changes are taking place in the agency such as; new building for the workshop is being renovated, another satellite will be starting soon from a PIC Grant and looks like HUD will be coming through with their long awaited and anticipated grant for a barrier free community residence.

ONTARIO COUNTY CHAPTERS — Abbey Industries has moved into their new 25,000 square foot facility in the town of Hopewell. This new building will allow the Chapter to serve an additional 50 to 75 people on a daily basis.

ORLEANS COUNTY CHAPTER — Open house held at the Orleans Association for Retarded Children in Medina, New York marked the completion of phase II of the Pearl Street Armory project begun three years ago.

Attended by more than 200 area residents, county officials and members of the business community, the event included a tour of the facilities which house the rehabilitative and vocational workshop and offices of the Orleans ARC in the armory's 10,000 square foot basement. Assemblyman Stephen Hawley was on hand to participate in the ribbon cutting ceremony in addition to Marcia Tuohey, mayor of Medina; Arthur Eddy, chairman of the Orleans Legislature; Mark Brandt and David Lettman of the N.Y. State Association for Retarded Citizens Inc. and key officials from the State Office of Vocational Rehabilitation.

Senator John Daly, who was unable to attend, received a citation of appreciation for his continued efforts and endorsements aiding the Orleans ARC. Assemblyman Stephen Hawley, Tony Gagliano, assistant director of community programs in West Seneca; David Kuhl, OVR Facilities Development specialist; and Robert Waters, head of the Armory Action Committee also received citation.

The first phase of the \$127,000 renovation project of the 80 year old former National Guard building completed in June, included installation of new fire walls and ceilings, and electrical, plumbing and heating improvements. During the second phase of the project, the newly renovated area was painted and readied for occupancy.

ROCKLAND COUNTY CHAPTER — conducted its annual bowling tournament on March 12th. Their opening event was expected to attract approximately 100 participants.

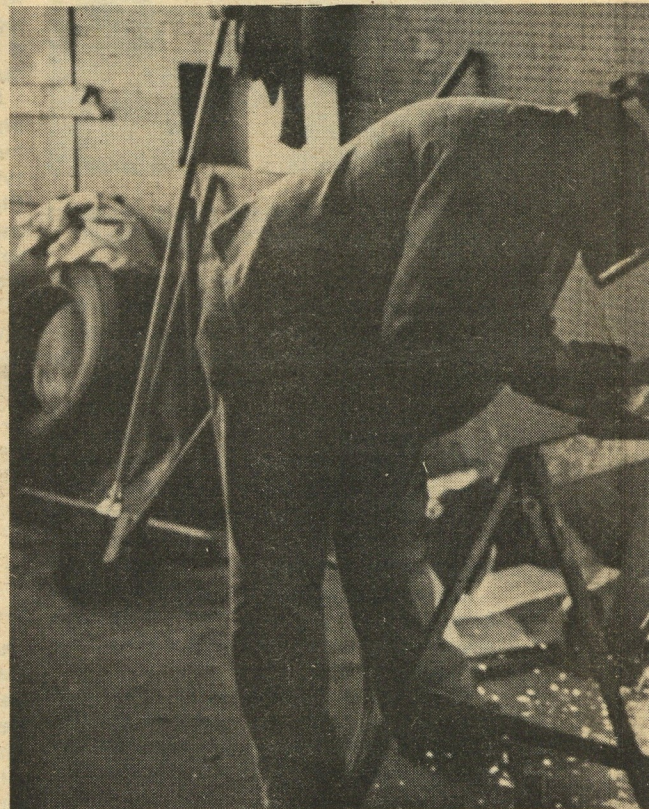


Attending the dedication, from left are, Warren Tompkins, Donald Levingier (both first Board Members of Chemung County ARC); John Bryant (current Board President); another first Board Member, Marie Crowley; Elmira Mayor Mary Pat Ciccariello; Irene Platt and Marc Brandt.

ERIE COUNTY CHAPTER — proudly dedicated its new \$2.2 million barrier free building as the Louis J. Billittier Center. This new building will allow Allentown Industries to increase its capacity from 210 to 300 clients by 1985.

FRANKLIN COUNTY CHAPTER — has recently opened a Children's Community Residence in the town of Moira. This program is specially designed for ten children ages 6 - 16. The residence has one respite bed available.

The Mohawk Valley fabricating Division will specialize in the construction of three-to-five-yard garbage dumpsters and Multi-Yard Roll-Off bins. MVF is also producing controlled draft wood stoves suitable as a camp or second stove. Mr. David Cook is the division's Senior Supervisor and Mr. Keith Hughes is the workshop supervisor. Both Dave and Keith have vast experience in the metal fabrication business; and their expertise and the commitment of Herkimer Industries' staff will assure a quality program and a very venture in prime manufacturing.



Herkimer Industries includes a new Metal

SARATOGA COUNTY CHAPTER — The Saratoga County Chapter, A.R.C., is now operating a Respite-Homemaker Service. This service provides a home-based respite care, training, and assistance program for families with developmentally disabled children. Respite Workers are placed in homes of families with developmentally disabled children and work with both the child and the parents. This service strengthens and stabilizes the family unit thus maximizing the growth potential of the developmentally disabled individual. (Disabled individuals living independently could also be served, if the need arises).

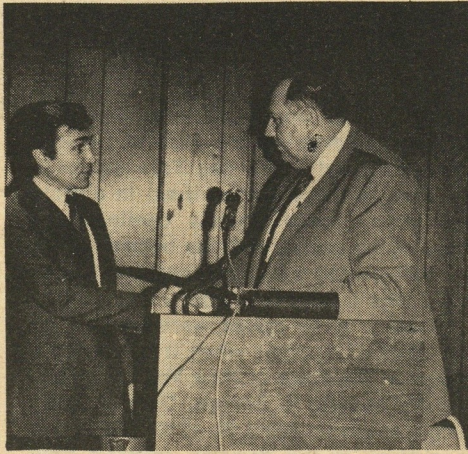
Ann Gurley, Coordinator of the Homemaker Services Program, states that by providing respite, teaching parenting skills, and assisting during times of crisis, stress is relieved in the family unit. Reducing the stress creates happier parents and a more solid and warm environment for the develop-

Our Chapters are doing for our children and adults

mentally disabled child. Besides enhancing the family environment for the child, this program establishes one to one training for the child in personal care tasks, independent living skills, socialization skills, and productive recreation. This special attention helps to maximize the child's growth potential.

STEUBEN COUNTY CHAPTER — has been elected to membership in the Screen Printing Association International. Screen printing is an integral part of the graphic arts and is used for advertising on banners, T-shirts, decals, etc. The Screen Printing Association International has members in 78 countries and provides members with technical and educational information.

ULSTER COUNTY CHAPTER — The Ulster Association for Retarded Children has announced it will again hold the Parent-Professional Team Work Conference during May 16th & 17th, 1983. The



At the Annual Dinner - Dance held by the Ulster Association for Retarded Children on December 3rd, 1982, the Ulster County Chapter awarded the First Annual Humanitarian Award to Mr. Maurice Hinchey, Assemblyman 101st Assembly District. The Board of Directors of the Ulster Chapter have decided to select an individual on a yearly basis who best demonstrates humanitarian qualities as related to supporting, assisting, and creating programs for the handicapped within the Ulster County limits. Mr. Hinchey as the Assemblyman in this district has not only supported Ulster ARC in its endeavors, but has carried many issues to the Legislature and the state bureaucracy on behalf of Ulster ARC. With a great deal of appreciation, Ulster ARC awarded the First Annual Humanitarian Award to Mr. Hinchey at this annual affair.

Mae VanDevelde of Wayne County Chapter, Association for Retarded Children, has been named Residential Staff Person of the Year by the Western Region NYSACRA (New York State Association of Community Residence Administrators), a group of 21 not-for-profit agencies who provide supervised housing to disabled people.

Mrs. VanDevelde was honored at NYSACRA's Annual Conference in Albany for her dedication, community involvement and advocacy for the people who live in ARC's Sodus Community Residence, located on Main Street.

Mae has been associated with ARC since 1967 as a volunteer, Supervisor of the Homemaker Program and, since April 1981, as the Senior Counselor for the Sodus Residence. She lives on Old Ridge Road, Sodus, with her husband, Robert, and one of her four children, Jack.



Mae VanDevelde
Wayne County Chapter ARC
Senior Counselor, Sodus Residence

Posters popular in Erie

Erie County Chapter provided a sensitivity awareness program for young people to further their understanding, awareness, and interest in mentally retarded persons. Over 150 persons were reached through a Poster Competition Program.

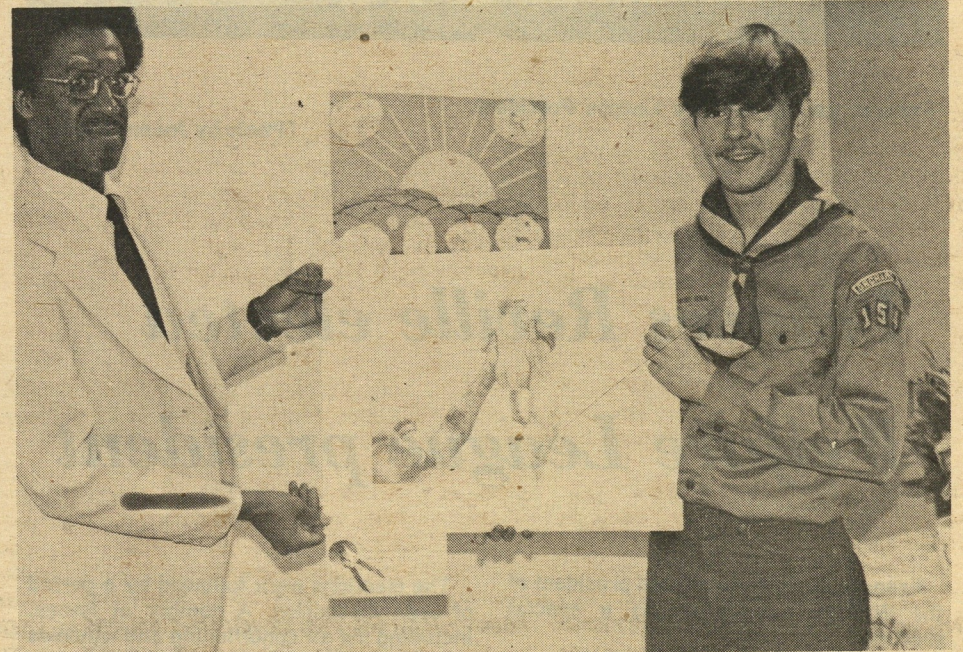
The competition required a poster in any flat medium based on one of the themes: "the Sun Shines on Everyone" or "Happiness Is Being a Good Friend". Girl Scout Troops, Boy Scout Troops, Campfire Clubs and Indian Guide Tribes were invited to participate.

Cash prizes of \$50.00 went to the winning entries in their Annual Poster contest, on

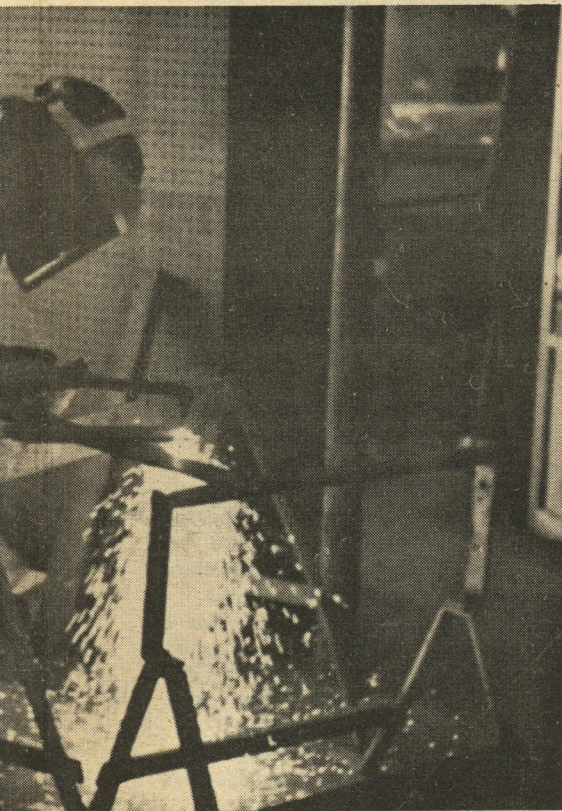
January 31, 1983, at a reception hosted by the Public Education Committee.

Brownie Troop No. 1070 of Kenmore, under the guidance of leaders, Mrs. Susan Yates and Mrs. Mary Kreher, submitted the winning entry in the seven to nine year old division. Girl Scout Troop No. 628 of Eggertsville, whose leader, Mr. Ronald Plesh, won in the fourteen year and over division.

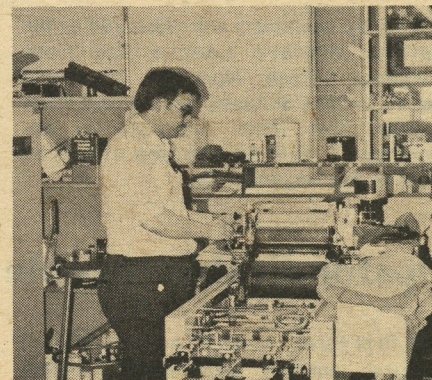
The awards were presented to the recipients by Mr. Sherman Conley, President ARC Board of Directors, in the Louis J. Billittier Center, where all poster entries were displayed.



Sherman Conley, President of the Board of Directors, Erie Chapter ARC and Kenneth Meiss, Boy Scout Troop No. 154, Orchard Park, winner, 14 years and over.



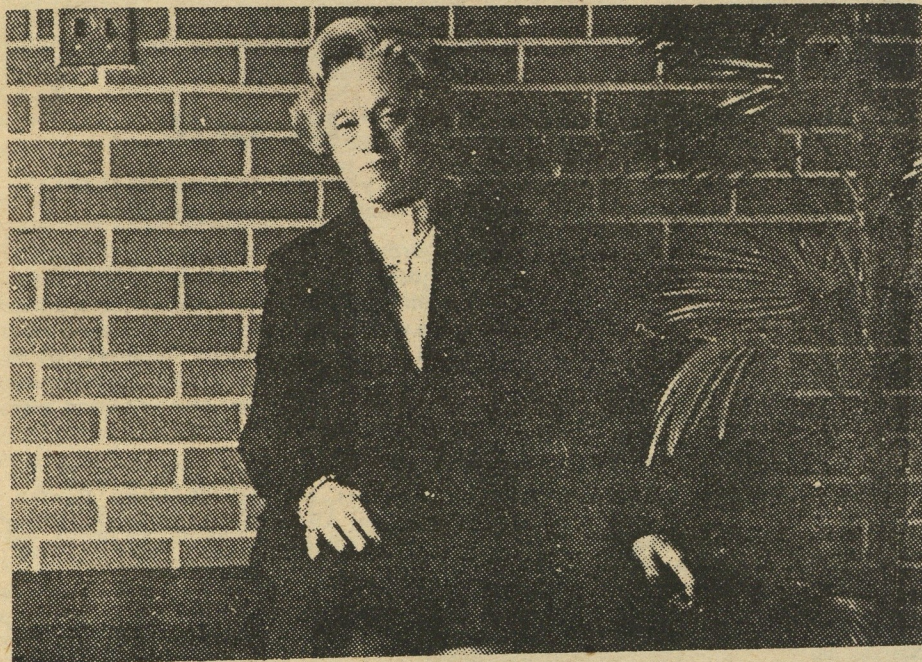
Wayne County Metal Fabrication Satellite Division.



Conference will be held at the Granit Hotel in Kerhonkson, New York and will feature sessions on guardianship and advocacy, parenting, service systems, medical and genetic counselling, and a trade fair which will be specifically directed toward service systems and parent availability. This conference will feature speakers such as Francis Berko, State Advocate for the Disabled, Betty Pendler, Chairperson of the A.R.C. Education Committee, Dr. Henry Muschio, Professor and Chairman of the Biological Sciences Department of Dutchess Community College, Rev. Paul Kelly, Board of Visitors New York State, and many more. The Conference Committee is currently putting together a schedule of speakers and participants which will be mailed out to the Chapters in the very near future. If anyone is interested in receiving this material and has not been placed on the mailing list, please contact Ulster A.R.C., 139 Cornell Street, P.O. Box 1278, Kingston, New York 12401.



The Wayne County Association for Retarded Children — Vocational Rehabilitation Center has been very busy expanding training programs and increasing public visibility. These programs include Printing Trades, Recycling, Janitorial Training Food Service. All of the programs provide relevant training for the clients and also generate income. An added advantage of these programs is the increased community awareness of the diverse services that the VFC offer.



Frances Reville, Welfare League President.

(Photo by Joanne Waters)

Frances Reville elected Welfare League president

Frances Reville was elected president of the Welfare League during a special meeting.

"We are all very familiar with Frances Reville," said Dr. Henry Siegel, the former president of LV's official parent organization, "and I am sure she will do an outstanding job as president of the League."

Having served as president of the Welfare League for four years in the early 1970's, Frances Reville has donated a great deal of her time, effort and experience toward helping developmentally disabled. In the past Mrs. Reville has held the position of treasurer of the New York State Association for Retarded Children, was a member of Letchworth's Board of Visitors and served on the New York State Institutions Committee.

In addition to her position as president of the Welfare League, Mrs. Reville is a member of the Board of visitors for Manhattan Developmental Center.

Stressing the importance of having Welfare League members stand as a "firm unit," Frances Reville said, "Now that we are faced with budget cuts, the time has come again for us to dedicate ourselves to the task of ensuring the well-being of all the children who live at Letchworth village."

Alan Hecht, the League's 1st vice president, introduced the newly elected officers and board members to the group of some 50 Welfare League supporters that assembled at the MED School. The officers included Frances Reville, president; Alan Hecht, 1st vice president; Lou Corbo, 2nd vice president; Maurice Fleishman, treasurer; Charlotte Roth, financial secretary; Goldie Gold, corresponding secretary; Helen O'Neill, recording secretary; Sam Schlieder, secretary and Zachary Sosis, sergeant-at-arms.

Michael Falk, Dorothy Gasman, Martha Plato, Beatrice Romano, Sam Solstein, Henry Siegel and John Slotwinski were elected to the Welfare League's Board of Directors with terms expiring in 1986. Also elected to the Board were Jack Bernstein, Bernice Cohen, Gae Mangano and James Mangano. Their terms will expire next year.

The elections were followed by a period of open discussion. A number of issues, including the air conditioning and windows projects, Social Security and the renovations currently being done on the Letchworth campus and at the discrete Unit at Rockland Psychiatric Center, were raised at this time.

Three WL members were honored at the meeting. Welfare League Luncheon chairperson Rose Horowitz presented plaques to Sam Solstein, Sylvia and Mike Newman and Irene Shockley in appreciation of their fund-raising efforts on behalf of the organization.

Tips for disabled people

The first three issues of a new series of brochures entitled **Independent Living Ideas** have been produced by President's Committee on Employment of the Handicapped.

The series has been planned to emphasize frank discussion of the challenges faced by the whole range of people with disabilities while providing concrete and realistic suggestions to aid in attaining a more independent life style. Currently available are: 1) **Job Tips for People With Mental and Emotional Problems**: offer information, as well as strategies and practical advice for those coping with these problems as they are encountered in the work site; 2) **Planning For A Job: Tips For Disabled Students** engages students in their personal problem-solving tasks and serves as a guide to realistic strategies and 3) **Marketing Your Disability and Yourself** which is a short case history of one learning disabled adult as she began to create a national organization and develop a personally satisfying career.

These materials focus on increased dignity, equality and independence for disabled adults. Single copies of these publications are available without cost from the President's Committee on Employment of the Handicapped, Washington, D.C. 20210.

Willowbrook Update

by Walter C. Redfield, Esq.

The decision of the United States Court of Appeals for the Second circuit on March 31, 1983 in the "Willowbrook" case makes clear that the "Willowbrook" consent decree and, in fact, the Federal courts will no longer serve as pillars of support in bettering the lives of persons who are mentally retarded. This applies at the least to those among them in a state institution. Judge Bartels confined the scope of the earlier hearing before him to "class" members and the appeal was from this Judge's judgment after that hearing.

Broadly, three issues were treated by the Court of Appeals when it decided the appeal of the State of New York from the decision of John R. Bartels, District Court Judge, made on April 28, 1982. The issues considered in the decision covered New York State's noncompliance with the consent decree, the need for and the propriety of the appointment of a Special Master, and the size of residences.

Faced with overwhelming evidence of manifold instances of the shoddy, unsanitary and mentally stagnating operation of Staten Island Developmental Center and of other facilities to which Willowbrook class members had been transferred, the Court of Appeals determined that the State of New York had not complied with the Willowbrook consent judgment. Since the State also had refused to and could not be compelled by a Federal Court to fund the review Panel, the court of Appeals found the appointment of a Special Master to be an appropriate alternative and one which a Federal court could compel the State of New York to financially support.

However the wide ranging beneficial criteria for the levels of care and services for OMRDD's charges were severely curtailed. Quoting from the June 18, 1982 decision of the United States Supreme Court in the case of *Youngberg v. Romeo*, the Court of Appeals noted that persons who are mentally retarded had only "a constitutional right to 'minimally adequate or reasonable training to ensure safety and freedom from undue restraint'." Having thus determined the required degree of training, the Supreme Court, which the Court of Appeals and Judge Bartels are obliged to follow, "found it unnecessary to consider 'the difficult question whether a mentally retarded person, involuntarily committed to a state institution has some general constitutional right per se, even when no type or amount of training would lead to freedom'."

Who determines whether or not an individual can be trained to attain a level which will "lead to freedom"? The Constitutional standard to be applied in reviewing state action for the protection of the involuntarily committed "requires that the courts make certain that professional judgment was exercised. It is not appropriate for the courts to specify which of several professionally acceptable choices should have been made."

Although the Court of Appeals upheld the appointment of a Special Master, it again quoted the Supreme Court with regard to the responsibility of a Federal court in a case presenting a claim for training to be given by a state. The decision respecting an individual's trainability and the training required, if made by a professional, although the professional is employed by a state, "is presumptively valid; liability may be imposed only when the decision by the professional is such a substantial departure from accepted professional judgment, practice or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment." Can this be demonstrated prospectively? I leave this to the professionals. The Court of Appeals, however, notes that time may show that because of *Youngberg's* restrictive effect upon the scope of permissible review of the decision made by

the state's professional, the Special Master is unnecessary.

On the final issue, the size of residences, the Court of Appeals directed that consideration must be given to the availability of residential sites, the relative cost of serving the individual resident in residences of various sizes, and the needs of the residents. These factors, however, must be balanced.

The decision of the Court of Appeals recites that, although it rejected other challenges to the action of the lower court, a different view was taken with respect to Judge Bartels' refusal to modify the "bed limitation on the size of community placement facilities."

After an extended discussion in the decision of "New York City's extremely tight housing market", "neighborhood opposition", the effect of the Padavan law, and the vastly differing opinions of the plaintiffs' and the state's experts as to the proper size of community placement facilities, the court reasoned that since there had been no suggestion that the state's experts testified in bad faith, it very likely could simply reverse the denial of the state's request for permission to increase the size of residences and itself grant the state's request. However, the Court of Appeals sent the matter back to Judge Bartels on the narrow issue whether the views expressed by defendants' experts, as to the propriety of the 50 bed limitation constituted "professionally acceptable choices" or were "such a substantial departure from accepted, professional judgment, practice or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment."

Although the Court of Appeals referred back to Judge Bartels the question of the size of the residences of persons who are mentally retarded for a hearing at which testimony and additional proof may be offered, its decision made clear to Judge Bartels that the state shall be permitted to increase the capacity of those residences.

The hearing on bed capacity is presently scheduled to be held on May 5, 1983 before Judge Bartels but in large measure the result appears to have been predetermined. Bed capacities will increase.

I suggest that this decision of the Court of Appeals culminates a line of court decisions which narrowly interpret the Constitution for the United States as it relates to the rights of handicapped persons and like results may be anticipated in litigation involving non-class persons who are mentally retarded.

As we go to press, we have been advised that Plaintiffs have requested a re-hearing before all of the judges of the Court of Appeals for the 2nd Circuit, rather than the three-judge panel which made the above decision.

As some professionals view parents.....

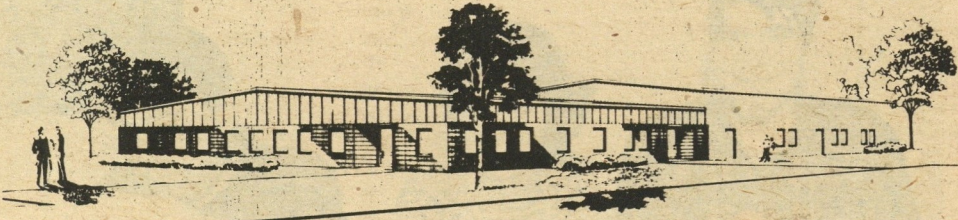
If the parent is militantly aggressive in seeking to obtain therapeutic services for his child, he may be accused of not realistically accepting his child's limitations.

If a parent does not concern himself with efforts to improve or obtain services, he may be accused of apathetic rejection of his child.

If a parent questions too much, he has a "reaction formation" and may be oversolicitous.

If a parent questions too little, he is branded as disinterested and insensitive.

Parents — remember we are unique kind of professionals ourselves, cutting across many disciplines and including many areas that can be beneficial to professionals and we are pleased to note that more and more parents and professionals are working towards understanding of our mutual goals which is to help our son or daughter.



Hershey, Malone & Associates
Engineers & Architects

New Facility Opens

The Ontario County ARC opened the doors to its new facility, known as Abbey Industries and Training Center, located in Hopewell, New York. The 1.2 million dollar structure offers the capacity to serve up to 200 clients in the modern workshop. Features of the new facility include an industrial kitchen, a large cafeteria, enclosed loading docks and modern offices. In recent years, the Chapter's previous location in Geneva had become too small for the number of clients needing services and for the types of contract work the agency is capable of handling.

Helping Rosemarys, we help ourselves

by Ned Pattison

Rosemary died last week. She had been dealing with the cancer in her 47-year-old body for about a year, but it was her heart that finally gave out. In her final days, she had a lot of support and comfort from her family and friends helping her deal with the end of life. All things considered, it was a good way to go. It certainly was better than an anonymous death in a cold cell, which is the way it might have been predicted in Rosemary's circumstances.

You see, Rosemary spent about 35 of those 47 years in confinement. If it weren't for the fact that she was retarded, it would have been called prison. But because Rosemary was not quite as sharp as the average citizen, at about the age of 5, she was sent off to an institution. Her parents really didn't have much choice.

In those days, there was a certain amount of shame that went with having a retarded child. It was assumed that really nothing could be done to help such a person to achieve her potential, whatever that might be. Indeed, the basic premise was that she had no potential. Society provided no help to bewildered parents upon whom this burden had been imposed — no special education, no training, no supportive services, no supplemental security insurance, no nothing. Sometime during her confinement, her parents died. The rest of her family hardly knew of her existence. It wasn't that they were hard-hearted or uncaring; in Rosemary's case, quite the contrary. When she was institutionalized, her brothers and sisters were small children. Rome was a long ways away, and the whole system was designed to make nonpersons of the inmates.

About 10 years ago, as a result of the process of deinstitutionalization following the Willowbrook Decree, Rosemary was sent back to Rensselaer County where she originally started.

At first she was placed in a community residence run by the retarded Children's Association. Soon she responded to their care and nurture. She learned to cook, care for herself and generally cope with the daily tasks of living in a cooperative way with the other residents. She progressed next to a daily job at a sheltered workshop, performing what to most of us would be fairly routine func-

tions, but to her were challenging. She rather quickly and steadily acquired social skills, a sense of humor, dignity, self worth and confidence. Just three weeks ago, one of her drawings won third prize in an art show and entrants from both retarded and non-retarded artists.

Finally, she was moved to another residence, this time to her own apartment with her own roommate, her own TV, clothes, kitchen utensils and food of her own choice, all of which she bought with her own money that she earned at work and that she managed herself. She still had help from the staff of the Retarded Children's Association, but only what she needed when some task stumped her. And they helped her old family, her brothers and sisters, aunts and cousins, to rediscover her, to get to know her, to cherish her. So now Rosemary had two families; her blood relatives, and her friends in the workshop, the residents, staff and volunteers in the Association. When the cancer came, they helped her deal with it; when death came, they grieved for her and comforted each other.

In the last analysis, in spite of those dreary years in confinement, Rosemary's last ten years were almost enough to make amends for the first 37. That, it seems to me, is a triumph that this society can feel damn good about. It is a story that has been repeated thousands of times over for thousands of our citizens who have been let out of the cages we put them in because they were a little different than the rest of us. It has happened as a result of a lot of people who simply wouldn't tolerate human beings being treated like animals; who dug in their heels and insisted that their government institute programs for the Rosemary's of this world to the end that they not be deprived of the right to achieve whatever potential they might have; who overcame the objections of their fellow citizens fearing that their property values would go down or that their own children would be attacked or contaminated by these "monsters". Our society did these things because we thought we were helping the Rosemarys. As it turns out, we were also helping ourselves.

So long Rosemary, it was nice knowing you.

Unique residence celebrates 1st anniversary

UNIQUE RESIDENCE CELEBRATES FIRST ANNIVERSARY

Livingston - Wyoming-Chapter

The nine residents of Letchworth House, a community residence operated by the Livingston - Wyoming ARC, had a wonderful time celebrating the one year anniversary of the opening of their home, March 8th. They enjoy a "common denominator" — age. All the people who live at Letchworth House range in age from 62-85 years, but this never seems to stop any of them from fully enjoying parties and other recreational activities.

The Letchworth House is unique both as compared with other ARC homes, and with what is provided in other state operated community homes in nearby counties. It is the only home in the area designed specially for the elderly and as such, its philosophy and operation are somewhat different. Based on the premises that people over the usual retirement age have the right to "take it easy" Letchworth residents are not required to attend a day program outside of the home. Some clients, all ex-residents of Craig Developmental Center, do attend workshop or day treatment programs on a full or part-time basis, but some choose to participate in in-home activities instead. This necessitates a different staffing pattern — at Letchworth some staff work

daytime hours, while at other ARC residences, all staff work evening, while residents attend day programs.

Due to the different schedule as well as the age and infirmity of the residents, a more enriched staff is needed, including residence manager, life skills instructor, community residence aides, live in staff, and staff to carry out day programming.

All the Letchworth House residents have participated in and have enjoyed a variety of activities planned throughout the year. Movies, meals out, senior nutrition lunches, trips to the library, bowling and get togethers with and at other community residences have been popular pastimes. "Special Events" included attending a Hot Air Balloon race, Senior Festival, Carnivals, Sidewalk sales, Planetarium and Craft fairs.

Never too busy for a celebration, the folks planned a lawn - party open house in June, and gave and attended several holiday parties.

Situated on three acres of land, the Letchworth residents were also able to enjoy gardening last summer.

As the one year anniversary of the Letchworth House approached, staff and residents alike looked back on the past 12 months as a pleasurable time. And, knowing their love for enjoyment, all will probably make the very most of the year to come, as soon as they stop celebrating!

Sullivan Director elected AC/MRDD Chairman

At the winter meeting of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, held in Washington, D.C., in January of 1983, Thomas J. Goodman, Ed.D., Executive Director, Sullivan County Chapter of the New York State Association for Retarded Children, was elected Chairman of the Board of Directors. This organization is the reorganized international Agency that sets standards for service to the mentally retarded and developmentally disabled throughout the nation. AC MRDD was formerly associated with the Joint Council on Accreditation of Hospitals (JAR) that was re - organized as an independent, not-for-profit corporation in 1979.

ACMRDD's accreditation process stresses agency self-renewal, education and development. It differs from government licensing which is an inspection and enforcement function usually focusing on minimal requirements for health and safety. There are two major aspects of the accreditation process, setting standards for services and determining the degree to which any given service complies with such standards. The current standards were developed with input from persons throughout the developmental disabilities field, including the direct involvement of more than 600 professionals and consumer advocates.

AC MRDD's standards cover all services for developmentally disabled persons. They stress individualization and normalization, which means helping each developmentally disabled person to live as normal a life as possible in his/her own way. Each individual, regardless of age or developmental level, must have a program plan designed and implemented via the interdisciplinary process. Review and revision of the plan must be a continuous and self - correcting process. Agency policies must recognize and protect the rights of individuals and their families. Each agency must be, or seek to become, part of a service delivery system that uses generic services whenever possible and specialized services when necessary to meet the identified needs of all DD individuals within the community it serves.

AC MRDD's standards are high. They represent a level of achievement that until recently did not generally exist, but the standards are goals that can and should be achieved and every Agency can benefit from evaluating its services against them.

The Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons is located at 5101 Wisconsin Avenue, N.W., Suite 405, Washington, D.C. 20016. Dr. Goodman would like to encourage all Chapters of the State Association to become familiar with the standards and the accreditation process and would be happy to provide further information to anyone who wishes to contact him at the Sullivan County Chapter in South Fallsburg.

OUR NEW ADDRESS:

New York State Association
for
Retarded Children, Inc.

393 Delaware Avenue

Delmar, New York 12054

PHONE:

518-439-8311

News from Syracuse University Press

**A PRACTICAL GUIDEBOOK TO ASSIST
LAY AND CLERICAL TEACHERS,
COMMUNITY COLUNTEERS, AND
RELIGIOUS**

**PERSONNEL MEET THE
EDUCATIONAL
NEEDS OF EXCEPTIONAL CHILDREN**

**THE EXCEPTIONAL CHILD —
A GUIDEBOOK FOR CHURCHES
AND COMMUNITY AGENCIES**

Edited by James L. Paul

Ministers, rabbis, priests, Sunday School teachers, Scout leaders, and youth counselors in various community organizations are among the many thousands who have enormous opportunities to work with and substantially improve the lives of exceptional children and their families. But, these people of ten find themselves lacking basic information about the needs of the children or knowledge about how to meet those needs. The Exceptional Child is the first book to provide practical guidance for these individuals.

The contributors — all knowledgeable and experienced professionals who have themselves also worked as volunteers in the church and community — describe the specific nature of the children's needs and problems and practical approaches to meeting these needs in jargon-free language, easily understandable to those

who have no background in psychology or education.

The book is full of numerous examples and one chapter is completely devoted to an autobiographical experience of a family with a severely retarded son. Another chapter specifically helps the minister, priest, or rabbi understand ways he or she can facilitate directly or indirectly the supportive role the congregation can play. Yet another chapter describes community resources and clearly outlines suggestions for assessing those resources through referral and advocacy procedures. The book contains a list of names and addresses of selected national organizations which can be contacted for help in dealing with specific disabilities.

The Exceptional Child will help to aid and guide handicapped children and their families and help to bring about a larger caring community for these children.

James L. Paul is Professor of Education and Acting Dean of the School of Education of the University of North Carolina, Chapel Hill. He has taught and written extensively in the areas of emotional disturbance, autism, learning disabilities, deinstitutionalization, and advocacy.

Available From: Syracuse University Press, 1600 Jamesville Avenue, Syracuse, New York 13210.

Niagara appoints

Cesana Executive



**Paul Cesana, Executive Director of the
Niagara County Chapter.**

The Niagara County Chapter is happy to announce the appointment of Mr. Paul Cesana as Executive Director.

Prior to his appointment to the Niagara County A.R.C., Paul worked at the United Cerebral Palsy Association of Western New York as the Associate Director of Residential Services and was later promoted to the position of Director of Adult Services.

Paul has also worked at the Chautauqua County A.R.C. as Director of Clinical Services and has served as the Chautauqua County Coordinator of Community Services for the J.N. Adam's Developmental Center.

Paul possesses a Master's Degree in Social Work from the State University of New York at Buffalo and also a Certificate in Mental Health Service Administration from the University of Buffalo, School of Psychiatry.

Through his many years of experience in the field of mental retardation and developmental disabilities, Paul had developed a strong background and expertise in the managerial areas of program design and development, fiscal management, manpower and labor relations, management of daily program operation, fundraising, program planning and evaluation, public relations and clinical skills.

Karin Burgess receives public service award

Karin A. Burgess of Cortland will become the first recipient of the Public Service Award of the Cortland Association of Life Underwriters.

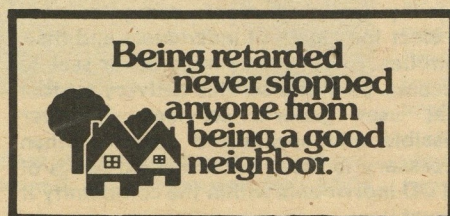
Burgess, executive director of the Cortland Chapter of the New York State Association for Retarded Children, has made many contributions in the mental hygiene field. Since 1970, she has been a volunteer member or held executive positions in numerous organizations for the mentally retarded, many of which she is still active in today.

Named a "Women of Achievement" by Zonta Club in 1979, she is a member of the Board of Visitors for the Syracuse Developmental Center, the state Council for Mental Hygiene Planning, a sub-committee of the County community Services Board and the Occupational Educational Advisory Council at Cortland - Madison BOCES.

She served as president of the Developmental Center's board from 1976 to 1978 and was reelected president in 1982. She also has been a member of the Cortland County Community Services Board's Sub-committee for Mental Retardation and Developmental Disabilities since 1979.

Burgess has been a member of the Council for Mental Hygiene Planning since 1977, serving as chairman since 1981, and prior to that served as chairman for the council's sub-committee for Mental Retardation and Developing Disabilities.

She was instrumental in the establishment of the Works Activities Center for severely retarded adults in Cortland County, and, as charter member and past president of the county chapter of the state Association for Retarded Children, was instrumental in the procurement of the first contract for mental hygiene services in Cortland County.



These young adults in the Nassau AHRC Day Treatment Program are hard at work assembling kits for the Chapter's annual April Teen Drive. At that time members of AHRC's youth go to their friends and neighbors to raise money on behalf of the mentally retarded.

Governor pledges community program support

Governor Mario M. Cuomo, in his message to the legislature on January 5, pledged continuing care to disabled children reaching adulthood, with the following words:

"Since the 1970's, New York State has increased its commitment to severely disabled children in education and social service programs. Many of these children are reaching adulthood and require continued residential care as they 'age-out' of child care programs. The hearings conducted by the Assembly have been particularly important in identifying this problem and proposing measures of community residential programs for all developmentally disabled persons who require such care. Where no programs are immediately available, we shall develop appropriate short-term, transitional placements, so that care for severely disabled young adults is not abruptly terminated.

"Where dependency can be avoided, especially when it robs people of their future and their self-worth, we shall marshal our public resources to give people the skills and education they must have to stand on their own."

WEINGOLD'S COMMENTS

Times Union
Mr. Dan Davidson
P.O. Box 1500
Albany, New York 12212

Dear Mr. Davidson:

One cannot but wonder how Governor Cuomo can reconcile his campaign rhetoric with what actually happened in the budget process.

Yes, the sudden appearance of \$50 million for shelters for the homeless is worthy — but — what of the hundred thousand or more mentally retarded who need or soon will need homes. Where is Governor Cuomo's support for community residences for the mentally retarded — who do not need intermediate (nursing) care facilities — indeed, are not eligible for Medicaid? What about his campaign promises that these are a special concern of his?

His program did not include the elimination of the meager funds for Camp Catskill, the only facility offering some

breath of another life for hundreds of institutionalized, as well as those in the community.

His promises did not include transferring helpless mentally retarded from Craig Development Center to non-existing beds in other institutions — for what? To house convicted criminals!

To those parents who ask, "What will happen to my retarded child when I die", his answer now is, "That's your problem. Let them become homeless first."

Oh, dear compassionate man, what are you doing?

Sincerely,

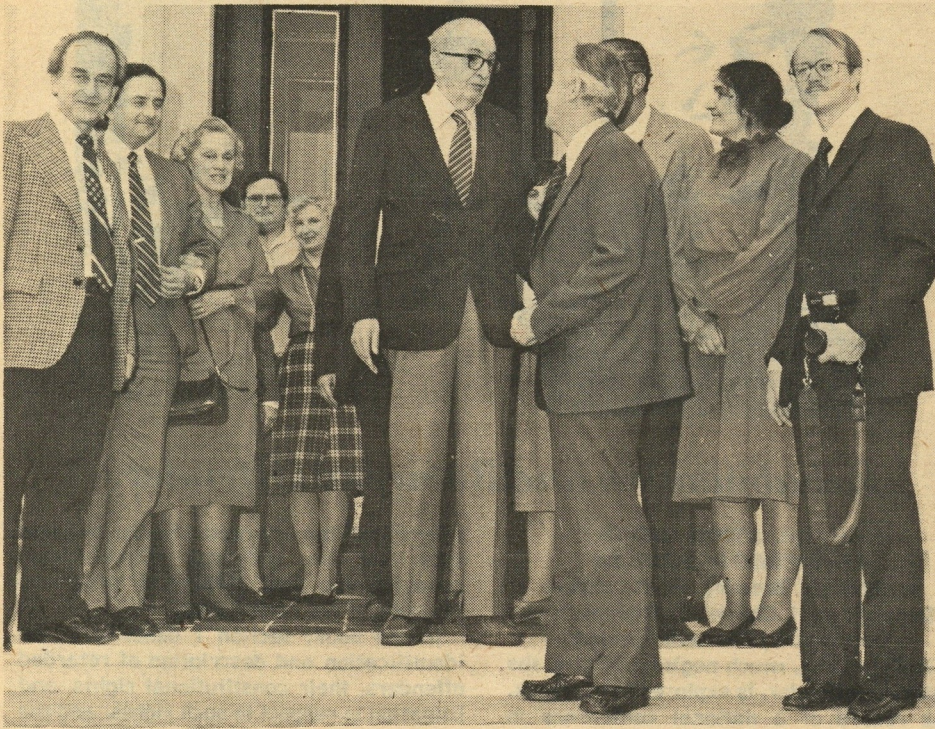
Joseph T. Weingold
Retired Executive Director
NY State Association for
Retarded Children, Inc.

Health care recognition in direct care

In recent correspondence with the Commission, Dr. Sterling D. Garrard, Professor of Family and Community Medicine and Pediatrics at the University of Massachusetts Medical Center, discussed the importance of direct-care personnel for the recognition of the seriousness of a client's medical condition.

Quoting from his own previously published comments, Dr. Garrard stated, "direct-care personnel are the first line of defense for health problems in many community residential facilities (CRFs). The identification of the presumptive signs of a health problem by direct-care personnel may be a pre-requisite for obtaining medical care for individuals who reside in CRFs with extramural health services. If a mentally retarded person cannot articulate complaints effectively, the ability of the direct-care staff to interpret non-verbal signs of behavioral changes is crucial. Failure of the staff to make a correct inference from the cues can be a temporary barrier to services. Training, experience, and familiarity with the mentally retarded person are helpful in making these interpretations."

IBR Hosts Seminar on Fragile X Prevention Committee



From left — Henry Wisniewski, Director of Institute of Basic Research on Staten Island, Dr. L. Shapiro, Frances Reville, two unidentified parents, Dr. Jervis, speaking with Dr. Clausen, Dr. Krystyne Wisniewski, Dr. Ted Brown.

A new approach for parent-teacher teams

The Bridge Model, an exciting new approach for building parent-educator teams for handicapped children developed by the Parents' Campaign for Handicapped Children and Youth and The Council for Exceptional Children, is now available in published form. A manual providing a complete guide for carrying out the highly successful training model has just been released.

The goal of the Bridge Model — to strengthen communication skills and positive working relationships among parents and educators — is woven into a sequence of planning activities culminating in a unique, highly motivating one-day workshop. The model has been tested successfully in urban and rural locations throughout the country. Although all the pilots have involved parents of handicapped children and teachers, the model is highly applicable to all situations in which it is important to foster collaboration based on mutual respect between parents of handicapped children and concerned professionals.

The manual contains step-by-step instructions covering all phases needed to produce the workshop, with a section on effective planning, a detailed curriculum

with how-to tips for all activities, and a guide to assist facilitators in conducting the training. In addition to disseminating the manual, the project staff will provide technical assistance to groups wishing to use the Bridge Model.

The project on which the manual is based was funded by a national training grant from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, Special Education Programs, to the Parents' Campaign and The Council for Exceptional Children. The Parents' Campaign is best known for its work in operating Closer Look, the national information center which serves thousands of parents of handicapped children. The Council for Exceptional Children is the foremost international association of educators of handicapped and gifted children.

Single copies of *The Bridge Model* are available free with a minimal charge for postage and handling. One hundred copies are available in Spanish. For a copy of the manual send \$2.00 to:

The Parents' Campaign for Handicapped Children and Youth
12091 16th St., N.W.
Washington, D.C. 20036.

Public Information Committee defines "working together"

A Policy for Public Information was adopted by the Board of Governors. In introducing the Policy, Kate Klein, Chairperson of the Public Information Committee commented, "We are the creators of the future for the Mentally Retarded in the hometowns of New York State. Our retarded have no past that was glorious to hold them strong in the face of adversity. Our organization is involved in actively advocating in a present that is uncertain. Let us act as though all we have is their future to work for and to build."

POLICY STATEMENT

It shall be the policy of the New York State Association for Retarded Children, Inc., that chapters will be responsible for public information efforts in their catchment areas; these efforts to include both association and chapter creative strategies.

Further, it shall be the responsibility of the Public Information Committee to assess, annually, the development of Association and Chapter efforts and to provide technical assistance, where indicated, to strengthen this united effort.

SPEAKING OUT

ALL PRESCHOOLERS SHOULD BE SCREENED FOR LEAD TOXICITY

by Robert Guthrie, Ph.D., M.D.

The new federal rule for reducing lead in gasoline will ease but hardly solve the problem of children's exposure to lead. Another needed step is mandatory blood-screening of preschoolers. And meanwhile, office physicians should forget the myth that lead menaces only the poor and initiate screening on their own.

The arguments for routine testing resemble those that forced the Environmental Protection Agency to propose a tightening of gas rules instead of an initially planned relaxation. A federal study indicates four per cent of children six months to five years old have blood lead above the danger point set by the Centers for Disease Control. A full 18.5 percent of poor black children are over the threshold, but even 1.2 percent of preschoolers from all families earning \$15,000 a year are, too. For urban preschoolers the proportion in danger is 7.2 percent and for their rural counterparts supposedly breathing clean air - it's 2.1 percent.

Of course, classic plumbism generally begins well above the CDC threshold, but there's strong evidence linking levels even below to impaired cognition, chronic irritability, and other "subtle" neuropsychiatric problems. And at 15ng, when no clinical problems are seen, lead can still inhibit enzymes used in heme synthesis. It's safe to predict the CDC will lower its blood threshold.

The branch for maternal and child health at the Public Health Service has urged that federal screening of children, now limited to the poor, be made universal. Instead, the Reagan Administration has cut \$2.5 million from the yearly \$10 million usually given for screening preschoolers in 60 cities. What's more, the remaining funds are now bundled into block health grants, allowing states to siphon off lead-screening money

for other programs. So it will be harder to find children who need to be taken away from lead-based paint, given a more protective diet, or treated with chelating drugs. Even cold economics can't justify this retreat. A University of Illinois study estimates that lead damage to children costs Uncle Sam \$1 billion a year, mostly for special education of the mentally handicapped. But the states could compensate for Washington's ruthlessness. In New York, I'm pushing for the introduction of a bill requiring annual testing of free erythrocyte protoporphyrin (FEP) for preschoolers. Those above the worry point of 50 ng-dL would next be directly measured for excess lead and the second possibility, iron deficiency. Right now, few states have widespread screening.

If more labs were set up for it, the FEP test of Columbia University's Dr. Sergio Piomelli would be convenient for office doctors. You mail in a dried spot of blood on filter paper without worrying about trace-lead contamination - a problem in blood collection for direct lead measurement. And a modification developed by my research colleagues simplifies the lab procedure.

We extract FEP with a more convenient and less toxic reagent - no need for a laboratory hood - and a St. Louis study shows no loss in accuracy. Either lab method would cost about 50 cents per test if done in volume.

In the past organized medicine has frowned on other kinds of mandatory screening as government meddling in medicine. Witness the AMA's opposition during the 60's to required screening of newborns with my PKU test. The lead threat demands a prompt change of heart. Children, with their vulnerable central nervous systems, can't afford to wait.

Dr. Guthrie is a professor of pediatrics, and microbiology at the State University of New York at Buffalo.

Group homes for mentally retarded grow 900% in past decade

There are now approximately 58,000 individuals residing in 6,300 community group homes for persons with retardation, according to a recent report by three participants in the Task Force on Fiscal and Program Planning of the National Association of State Mental Retardation Program Directors.

Those figures represent a growth rate of over 900 percent in the past ten years, and indicate significant progress in both deinstitutionalization and in making community residential facilities available.

A Report on the Availability of Group Homes for Persons with Mental Retardation in the United States was prepared by Matthew P. Janicki and William Eppie of the New York State Office of Mental Retardation and Developmental Disabilities, and Tadashi Mayeda of the University of California at Riverside. It is the hope of the authors that the report will provide a framework for the continued sustenance and development of all types of residential options for persons with mental retardation or other developmental disabilities.

The report is based on a telephone survey of each state's mental retardation-developmental disabilities agency. Of the 6,302 group homes reported, 91 percent were homes of 15 beds or less. About two-thirds of the homes were operated by nonprofit agencies, 18 percent by proprietary agencies, and 13 percent by government.

The survey revealed that there are at least 68,000 non-institutional beds nationally available in community home-like settings specifically for mentally retarded persons, and that an additional 55,000 beds should be made available to meet the out-of-home group living needs of individuals with mental retardation.

According to the authors, growth can only be sustained when such programs have a sound fiscal base and a well-developed program structure. The stability of funding for the programs is most critical to its future, whether emanating from the state legislatures, Title XIX Medicaid payments, or other sources.

OUR NEW ADDRESS:

New York State
Association for Retarded
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393 Delaware Avenue

Delmar, New York 12054

Phone:

518-439-8311

Westchester staff member writes on worlds of gifted and retarded

SPRINTING TO THE ENDS OF A BELL-SHAPED CURVE

By Paul Levine

Sometimes I feel as if I'm sitting on top of a bell-shaped curve looking through binoculars. Toward one end is my work as a counselor with retarded adults in White Plains. Toward the other end is my life with my two daughters, both of whom have been in talented and gifted programs in New Rochelle.

I often wonder why I am so comfortable as I go from one world to the other. But there I am walking out into the far reaches of the skewers they represent. Toward one end are "thinking exercises," independent research, and Iowa test results that nudge the upper limits of the graph paper.

Toward the other end is my job in a vocational - rehabilitation center, where the floors are color coded so the clients will know where to go. Where the labels of "backward" and "retarded" are worn as obviously as sandwich board signs, and where touring visitors whisper, "there but for the grace of God go I."

I guess I need each world so that the specialness of the other can be put in perspective. I need my daughters' world of trips to Stratford, Conn., and the New York City Opera so I can deal with grown men who carry Patridge Family lunch boxes.

So there is my eighth-grade daughter in the Izod blouse telling me she wants to go to Princeton and asking me what Columbia was really like. I need her asking me for help with polynomials and factoring so I can deal with a 45-year old man who sleeps in his clothes every night. I need her asking me for hints in remembering formulas for tangents and cosines so I can deal with a client who bangs his head with his fist every time he feels tense. I need to attend her All County Choir concert for yet another year and visit the library where her painting of a Japanese maiden is on display, so it will be easier for me to deal with a young man who keeps jumping because he can't concentrate on his work.

And then I am listening to my sixth-grade daughter tell me she was appointed to the school newspaper. She is in a program where "is willing to take risks" and "displays growth in problem solving" are graded on her report card. I need her asking me whether her independent - research report should be on Greek architecture or Greek literature, so I can deal with adults who are unable to tell the difference between a nickel and a dime.

And then I need to see clients who struggle to reach the point where they can be placed in a regular job outside the workshop so I can realize that reading scores four grades ahead are not the greatest achievement in life. I need to see the happiness of someone who learns to ride the public bus so I can accept the idea that going to the best schools and earning multiple degrees are not the most important goals.

Diet recommended to counteract medication

In response to a Commission request to review the weekly menus of an upstate developmental center; the State Commissioner of Health, Dr. David Axelrod, has recommended a diet high in fiber content to help counteract the effects of anti-seizure and other constipating medications.

Specifically, the Commissioner of Health recommended the following preventive actions.

- Whole grain cereal and/or bread at every meal.
- Salads at lunch and dinner.
- Two servings of raw fruit daily.
- Inclusion of prunes and/or prune juice in the menu.

Oh, it's easy for me to sit at school meetings and listen to such topics as the future of the talented and gifted program and whether the program should be graded or nongraded. Not like the parents of the retarded who come in for conferences. You can see them listen and feel them listen for something positive. Sometimes you can hear how hard they listen by their silence.

In my spare time I write, and I visited my younger daughter's school some months back and gave a talk on creative writing. Although only in the fifth and sixth grades, many of the children had already started writing stories and poetry.

At work I also share my writing. I run a poetry group. It's strange, I guess, running a poetry group for retarded individuals. But they love it. And they come each week without being reminded. Most of them listen as I read a poem or a short story. But a few clients try to write some lines and there's one woman who brings in the copied words of songs she has heard. That's poetry to her. They want to learn, just as my daughters want to learn. They need what I give, just as my daughters need what I give.

So there I am. Sliding down and sprinting to the ends of the bell-shaped curve. Oh, so easily. First in one direction. And then the other. To one a counselor. To the other a father. Embracing the specialness they have. Each in their own way.

Foundation demands changes in science fiction game

Protest effectiveness is evident in a report by Epilepsy Foundation of America, on a game protest to the manufacturer.

TSR Hobbies, the nation's leading producer of fantasy games, has agreed to delete reference to epilepsy and hemophilia from one of its games following protests from the Epilepsy Foundation of America and the National Hemophilia Foundation.

Dr. Eli Goldensohn, president of EFA, wrote to the president of TSR Hobbies, Inc., protesting the inclusion of epilepsy in a science fantasy hole playing game called "Gamma World."

"Gamma World" is a futuristic variation of the "Dungeons and Dragons" games produced by the same company.

It is played according to a rule book designed by the company, and is set in a post-nuclear war society in which bands of humans and mutated beings of all kinds roam a ruined landscape.

The epilepsy reference came in a list of what the rule book called "mental mutations."

Most of these are of a fantastic nature — like the ability to generate fire at will — but epilepsy is defined as a temporary paralysis that lasts various lengths of time.

Dr. Goldensohn, on behalf of EFA, protested the distortion of epilepsy, and its being described as a mutation of any kind.

Representatives of the National Hemophilia Foundation made a similar protest regarding the appearance of hemophilia as a "physical mutation." TSR spokesman Dieter Sturn expressed the company's regret that either condition had been listed, and said that there was no intention of causing distress or of offending people with epilepsy or with hemophilia.

He said that TSR Hobbies considers itself a responsible company, and that neither condition will appear in new editions of the game, currently undergoing a complete reprinting and redesign.



Rehabilitation and Retarded Offender

REHABILITATION AND THE RETARDED OFFENDER

by Philip L. Browing, Ph.D., editor.
Springfield, IL Charles C. Thomas, 1976
Reviewed by Dr. Jack Gorelick

A disturbing, much neglected issue, the retarded offender, is explored in this book, the record of a national conference to which a select group of experts was invited to make formal presentations on their specialties as well as to "brain-storm" in open discussions. The result is a sensitive exploration of the complexities associated with rehabilitating mentally retarded offenders. This is a pioneer endeavor in both the law, and, most specifically, in the criminal justice system, as well as in mental retardation.

Too often, the mentally retarded offender is rejected by the very people who could help him the most. Mental retardation agencies are reluctant often to assist the retarded offender because they consider him a criminal first, and mentally retarded second. Correction agencies

often reject the retarded offender because they feel he will not benefit from rehabilitation and treatment programs because of his retardation.

In the book, section I deals with the identification and description of retarded offenders, their constitutional rights, and litigation in respect to such rights, and the legal system as it applies to this group. Section II presents the philosophy and goals of rehabilitation and correction personnel with interventions aimed at integrated in the community.

The Epilogue lists 13 premises for interested persons that will provide a foundation for future action. For example, "no person should be incarcerated unless he or she is imminently dangerous to others." An excellent selected annotated bibliography on this specialized topic is included. This book is highly recommended for parents and professionals who are prepared to grapple with a difficult problem for which at present there are more questions than answers.

Tully sponsors youth involvement

Legislation sponsored by State Senator Michael J. Tully, Jr. (R-C, Roslyn Heights) that would increase the membership of 16 and 17-year old minors in not-for-profit community corporations has won committee passage in the State Senate.

Under Tully's proposal, which is expected to be acted upon by the full Senate in the next few weeks, more than one youngster would be permitted to sit on the board of directors of not-for-profit community recreation, educational, and "youth development and delinquency prevention" corporations.

"Many such corporations receive federal and state funding under various programs and, therefore, should be allowed to benefit from the input of young persons below 18 years of age," Tully explained.

He added, "The proposed change, in the composition of the board of community corporations will serve to safeguard the

interests of minors serviced by such corporations and further encourage their involvement in the decision - making process."

Under current State corporation law, youth board membership involvement is limited to not-for-profit "educational" or "recreational" categories. The proposed amendment would further expand the classification to include "youth development and delinquency prevention" community organizations.

Tully expressed the hope that recent publicity surrounding teenage drunk driving and the formation of community-based organizations to deal with the problem will further serve to underscore the need for greater youth participation in not-for-profit corporations that seek to incorporate.

"At a time when people are quick to criticize our young people it is gratifying to know that they will become involved and responsible," Tully concluded.

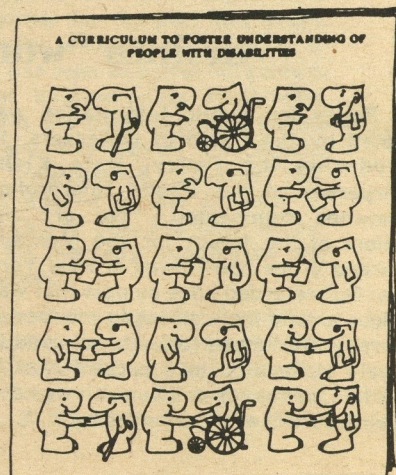
Four special booklets developed by Hunter College

Hunter College has developed four booklets designed to be integrated with existing curricular social studies, science, health education and English literature.

They are: *Staff Orientation Manual*, *The Handicapped in Literature*, *The Handicapped in Society*, and *Science and Health Education Perspectives on the Handicapped*.

The four booklets are now available as a set at a cost of \$6.00. All orders must be prepaid.

They can be ordered from:
New York State Education Department
Publications Sales Desk
Room 164, Education Building Annex
Albany, New York 12234



PARENTS RIGHTS: SOL GORDON '75

*Parents of exceptional children
should realize they have these rights!*

- Freedom to feel they have done the best they could.
- Freedom to enjoy life as intensely as possible, even though they have an exceptional child.
- Freedom to let their handicapped child have his or her own privacy.
- Freedom to have hostile thoughts once in a while without feeling guilty.
- Freedom to enjoy being alone at times.
- Freedom to tell people about their child's progress and achievements with a real sense of pride.
- Freedom to have their own hobbies and interests.
- Freedom to tell teachers and other professionals what they really feel about the job the professionals are doing and demand that their opinions be respected.
- Freedom to devote as much time as they want to the handicap cause and to get away from it for a while and return if they want.
- Freedom to tell their child if he or she displeases them even though their child has a handicap.
- Freedom to refrain from praising their child gratuitously, even though they have been told to offer much praise.
- Freedom to lie once in a while and say everything is fine, and not to feel compelled to tell the truth to everyone who asks.
- Freedom to say at times that they do not want to talk about their problems or their handicapped child.
- Freedom to have an annual vacation without the children; have dates, celebrations, weekends away, time together to enhance their marriage.
- Freedom to spend a little extra money on themselves, even though they feel they can't afford it.

Serious about Semantics

Joseph T. Weingold, Guest Editor of Our Children's Voice and former Executive Director of NYSARC (1950-1980), took issue on the origin of Motivation for Community Placement with Editor of Mental Retardation, Downsview, Ontario.

In a letter discussing motivating factors, NYSARC's Honorary Member of the Board of Governors, Weingold wrote:

"I should like to call your attention that the major premise, expressed in several articles in the Autumn, 1982 issue, that community placement derives from the 'deinstitutionalization thrust' is incorrect. Conclusions drawn in article after article from this premise are, therefore, wide of the point.

The original thrust for Group Homes began in the late 50's in New York State and became formalized in law in 1966. The impetus came, not from 'deinstitutionalization' (with which I have little quarrel) but from the cry of the parents who never institutionalized their retarded

children, 'what will happen to my child when I die?'

It became evident, as the original pioneers grew older, that most of their children could not live independently in the community. Institutionalization, after a lifetime of community service participation, was unthinkable. Hence the movement towards a continued life style in the community.

The tail is indeed wagging the dog today. Against some 12,000 mentally retarded persons in institutions in New York State, there are over 500,000 in the community. Yet, funds for institutions and 'deinstitutionalization' are some \$500,000,000 against less than 5 percent that for community facilities.

Something is terribly wrong — and it is being aided and abetted by a professional community that doesn't understand the root and dynamics of the movement towards community residences.

Orphan drugs need exploration dollars

In signing legislation to address the high cost of drug research for new diseases, President Reagan explained:

"This legislation exemplifies the proper role of government in helping meet legitimate needs in those cases where the free market alone can't do the job. . . I only wish that with the stroke of this pen I could also decree that the pain and heartache of people who suffer from these diseases would cease."

After clearing both houses of Congress unanimously, the Orphan Drug Act was signed into law by President Reagan on January 4, 1983. The bill provides incentives in the form of tax credits to pharmaceutical companies that develop drugs for treating rare diseases.

In signing the bill, the President remarked that in spite of leading the world in the development of new drugs over the past century and saving millions of lives in the process, no drugs had been developed for relatively rare diseases such as cystic fibrosis, Wilson's disease, myoclonus, Tourette's syndrome, and certain neuromuscular disorders and cardiac arrhythmias.

"The cost of discovering and developing a new drug is often staggering," the President explained. "By definition, an orphan drug is one that treats a disease that affects 200,000 or fewer individuals — and, from an economic perspective, groups that small do not now justify the kind of research expenditures that companies must make.

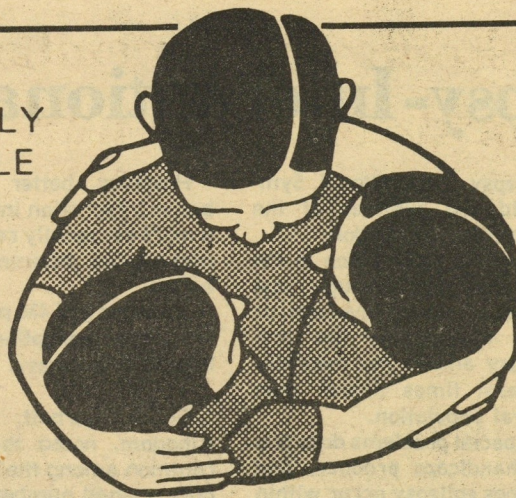
Specifically, the bill provides an elective nonrefundable income tax credit of 50 percent of 'qualified clinical testing expenses' which are necessary in obtaining the approval by the Food and Drug Administration for the commercial sale of a drug for a rare disease.

The Federal subsidies have been estimated at \$75 million over the next five years of firms that produce drugs to treat some 2,000 diseases.

The President also pointed out that the Department of Health and Human Services established an Orphan Products Board in March 1982, with membership and functions similar to those in the bill.

"This bill will enhance the steps we have already taken to encourage the development of orphan drugs," he added.

THE FAMILY CIRCLE



For the vast majority of the world's disabled the main agent of rehabilitation is a strong well advised and well supported family.

Did you know that.....

— The Public Employment Relations Board (PERB) has ruled that retirement benefits are subject to arbitration. This role was confirmed by a court decision of the Appellate Division.

PERB Counsel Martin L. Barr stated what is not worthy about the decision is the Court's interpretation of the Constitutional provision of the State Constitution which has a reduction of retirement benefits once granted.

Barr believes that decision is the first to hold that existing retirement benefits may be diminished through bargaining.

— If your child . . .

— does not turn to face the source of strange sounds or voices by six months of age.

— has frequent ear aches or running ears.

— talks in a very loud or very soft voice.

— does not respond when you call from another room.

— turns the same ear toward a sound he/she wishes to hear.

These are called warning signals of a hearing problem.

ACCESS STUDY

— Equitable access to health care for all

Americans is an "ethical obligation: as society, even at a time of budget cutbacks and fiscal austerity," a Presidential commission said in completing a two-year study. The 11-member commission was headed by Morris B. Abram, former president of Brandeis University.

SAFETY SEAT REACTION

— Fifty-two percent of New York State's motorists are complying with a new law requiring children under age 4 to be strapped into car seats, a State University of New York (SUNY) survey shows.

Although better enforcement could bring the compliance rate up to 75 percent, the New York figure is higher than in the other 20 states with similar laws.

"BLESSED BE"

— NYSARC Public Information Committee has the film "Blessed Be" for loan to Community Residence Directors. This is an "up attitude" film on the joys of working with the handicapped.

Request from State Office.

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

"MEDICARE"

— Senate Democrats have formed a Medicare Task Force to make sure "Medicare does not face the same financial crisis that afflicts Social Security."

Pierre Pelican sends Special Olympics delegation to Louisiana

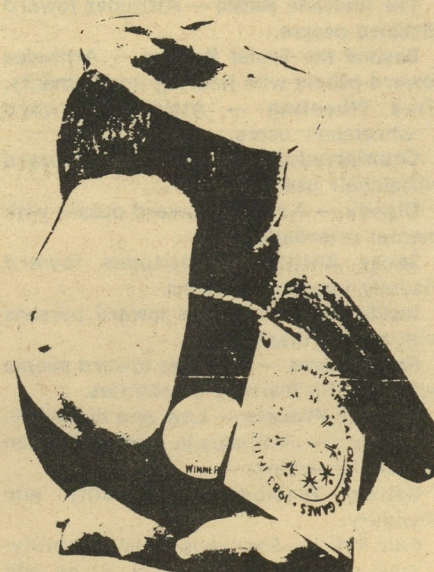
"Pierre Pelican", is a 10-inch tall, brown pelican, with a blue beret and a big yellow beak. He has been designated the official mascot of the 1983 International Special Olympics Summer Games. Pierre, can become yours for only ten dollars!

Proceeds from the sale of Pierre Pelican, will be used to help defray the cost of transporting 100 athletes and 25 coaches to the 6th International Special Olympics Summer Games, which will be held July 12-18, 1983, in Baton Rouge, Louisiana. The International Games will involve 4,000 mentally handicapped athletes from every state and 40 other nations.

New York Special Olympics provides year round sports training and athletic competition for mentally retarded children and adults. In New York State, there are currently 38,000 Special Olympians and 167,000 Volunteers. These Special Olympians are now preparing for the 1983 New York Special Olympics Summer Games to be held June 17-19, 1983 at the State University of New York at Albany.

You can help to pledge your support to New York Special Olympics by providing Pierre with a home. Call now to order Pierre Pelican at 370-4816.

Contact: Joann Marsala, Assistant to the Director of Development (518) 370-4816.



PIERRE PELICAN

Epilepsy-International View

The 14th Epilepsy International Symposium was held last summer at the Grosvenor House Hotel in London.

Epilepsy and mental retardation in the United Kingdom show that although most people with epilepsy are of average or above average intelligence, the prevalence of epilepsy among the mentally retarded is several times higher than among the general population.

What kinds of special problems does this combination of handicaps produce, just how frequently does epilepsy occur within the mentally retarded population, and why?

Several speakers addressed these questions during the Symposium.

Professor J. Bicknell noted that epilepsy among the mentally retarded may be a continuation of childhood epilepsy, or it may be the return of a previous condition, or it may be a new development.

Autism, Dr. Bicknell said, is often associated with the subsequent development of epilepsy.

The combination of epilepsy and mental retardation, each of which carries some social stigma, is often a "last straw" for families, she continued, and it is common for many restrictions to be placed on the lives of people who have both disabilities.

"These people are faced with families who have very low expectations of them, they develop low self-esteem and may become rebellious," she said.

However, better control of seizures, better integration into the community and a more personally rewarding life style can make a big difference in their lives, she added.

In a study of 436 patients with moderate or severe retardation, 93 had epilepsy or a history of epilepsy.

Dr. J. Corbett, also of the United Kingdom, noted that while epilepsy is common among the mentally retarded, in only a small number of cases can mental deterioration be seen as the cause.

"Both are more likely symptoms of an underlying condition," he said.

He noted that studies have reported that 31 percent of 21,000 people in an institution for the mentally retarded in the U.S. had a history of epilepsy, and that of these, 22 percent were receiving drug therapy.

A study of mentally retarded people in Aberdeen, Scotland, he said, revealed that between 27 and 50 per cent had epilepsy.

Seizures in early infancy seemed to be linked with severe retardation, he said.

Also, the risk of recurrence of epilepsy once it has been controlled, or is in remission, seems to be linked to the severity of the mental retardation, Dr. Corbett said, adding that the more severe cases tended to have a higher relapse rate.

Epilepsy has not been thought to be associated with Downs Syndrome, he said, but reported finding, on ten-year follow-up of mentally retarded children, that eight of thirty-two children with Downs Syndrome had later developed seizures.

Dr. Corbett also noted that there was a persistent decline in the amount of epilepsy in older mentally retarded populations.

Unfunded but not forgotten

by Donald C. Linkowski, Ph.D.
Director and Elaine Makas
Coordinator-Research Associate

The Regional Rehabilitation Research Institute on Attitudinal, Legal, and Leisure Barriers (RRRI-ALLB) lost its funding more than one year ago. However, the staff is committed to the continued dissemination of the many products of our six years of funding by the National Institute of Handicapped Research, U.S. Department of Education. As a result of some serious belt-tightening and the continued moral support of The George Washington University, we've managed to stay afloat for the past year at a new off-campus location. Rather large inventories and some creative budgeting have allowed us to continue disseminating our materials at cost.

We truly believe that we can continue this dissemination aspect of our work with a little help from our friends. We're not asking for something for nothing. What we are asking for is the continued use of our publication.

ONE DOLLAR BUYS

The Invisible Battle — Attitudes toward disabled people.

Beyond the Sound Barrier — Attitudes toward people with hearing impairments.

Free Wheeling — Attitudes toward wheelchair users.

Counterpoint — Attitudes toward wheelchair users.

Dignity — Attitudes toward people with mental retardation.

Sense Ability — Attitudes toward visually impaired persons.

Inside Out — Attitudes toward persons with hidden disabilities.

Perspectives — Attitudes toward people with specific learning disabilities.

Overdue Process — Law and disability.

Partners — Attitudes in a rehabilitation counseling setting.

Getting Together — Sexuality and disability.

Fair Play — Recreation and disability.

Your support of our publications will encourage us to continue our effort to reduce attitudinal barriers that hinder both disabled and nondisabled persons.

Kovler joins State ARC office

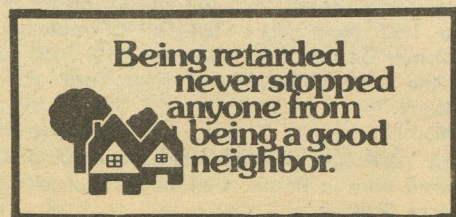
Joseph Kovler, OMRDD's director of program design and policy analysis since April 1981, has left State employ to become the State Association for Retarded Children's Associate Executive Director.

A Phi Beta Kappa graduate of SUNY Buffalo with a degree in Sociology, Mr. Kovler earned a Master's degree in rehabilitation counseling from SUNY Albany. He obtained his initial experience in human services in 1972 working with young people on his native Long Island.

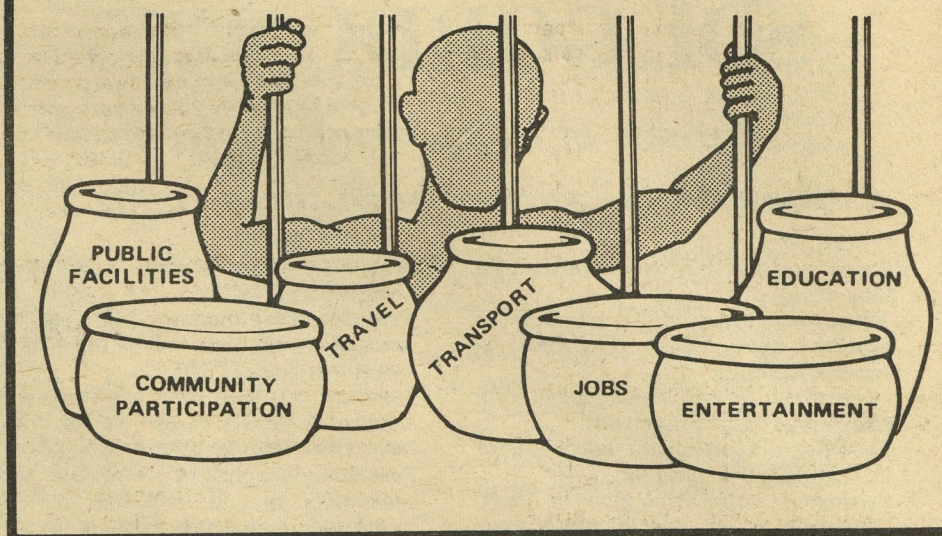
Following graduation from college, he was employed by the Nassau County Association for the Help of Retarded Children working in the agency's summer activities programs.

He has been a rehabilitation counselor intern with both the Albany Association for the Blind and Montgomery County ARC and a rehabilitation counselor for The Workshop of Menands, also in the Albany area.

Mr. Kovler joined the former Department of Mental Hygiene in 1977 as a rehabilitation specialist with the Eleanor Roosevelt Developmental Services here. He came to the central office as a member of the former upstate placement unit in October of that year. Since that time he has served in positions of increasing responsibility in policy development.



LOCKED OUT OF LIFE



World wide, 450 million people have a physical or mental impairment. For most it is the exclusion by society which makes that impairment into a true disability.

Peter Sullivan, *Sunday Times*, London

Interdisciplinary work in medical settings

by James A. Mulick, Ph.D.

Mental retardation professionals originally trained in a variety of disciplines increasingly practice in service settings "belonging" to other disciplines.

This has developed as a result of modern notions of interdisciplinary collaboration and comprehensive service planning. Thus, preparation for a career in the field of mental retardation now requires training that goes beyond the traditional confines of one's own primary discipline in order to facilitate effective and cooperative work with professionals having quite different academic backgrounds.

Some understanding of what other disciplines are trained to do and the scope of the knowledge base they are able to draw upon is needed to interact effectively with them around the complex needs of individual clients.

Since the early 1960's a major resource for advanced interdisciplinary training has been the network of University Affiliated Program (UAPs) in Mental Retardation and Developmental Disabilities. The basic model used is to unify training across many disciplines in a single setting where the values and resources of the university can be focused on issues related to service needs of mentally retarded persons.

Several recent books have emerged from the UAP system that highlight the value of an interdisciplinary approach in a medical setting.

Children With Handicaps: A Medical Primer by M.L. Batshaw and Y.M. Perret (ISBN 0-933716-16-8: Paul H. Brookes Co., 1981) is an excellent text for nonmedical disciplines. About 400 pages including a glossary of terms, a listing of syndromes, and a directory of agency resources — including UAPs — the book presents a very readable account of biomedical factors in developmental disabilities.

Heredity, the birth process, the function of various organ systems, and in-depth consideration of major handicapping conditions are all covered. The last part of the book addresses emotional aspects of caring for a handicapped child and raises significant ethical questions. The authors are sensitive to the orientations of other disciplines and show how their contributions are essential to a more complete understanding of normal and abnormal development.

DOWN'S SYNDROME

A truly remarkable contribution on Down's Syndrome has been provided by S.M. Pueschel and J.E. Rynders, entitled **Down's SYNDROME: Advances in Biomedicine and the Behavioral Sciences** (ISBN 0-938552-50-3: The Ware Press, 28 Hurlbut Street, Cambridge, MA 02138). Review of a pre-release copy prompts me to suggest that this volume will be a major reference on the subject during the 1980s. It provides critical reviews of the growing literature on the history, epidemiology; etiology; cytogenetics, and biomedical characteristics of Down's Syndrome.

Part II reviews the behavioral science and educational literature with emphasis on how an understanding of basic developmental and learning process can help us promote intellectual growth and independent living in persons with Down syndrome. The book is scholarly and up-to-date. A companion volume by S.M. Pueschel and L. Steinberg, **Down's Syndrome: A Comprehensive Bibliography** (ISBN 0-8240-7158-1: distributed by The Ware Press) lists more than 6,000 citations in the bio-medical and behavioral literature through about 1978.

Psychological Assessment of Handicapped Infants and Young Children (ISBN 0-86577-046-8: Thieme-Stratton, Inc. 1982) by G. Ulrey and S.J. Rogers is a well designed, useful, soft-cover book of particular value to any discipline working with high risk infants. I know of no other comprehensive text that does as well in covering the theoretical, developmental, and technical aspects of accurate psychological assessment of the very young atypical child. Special attention is paid to the assessment encounter, the effects of specific handicaps on expected developmental sequences, to Piagetian concepts, and to the array of instruments available for early childhood assessment. It is also an important book for psychologists doing diagnostic or consultative work with handicapped children.

BOOKS RECEIVED

Brown, D.A. **Reading Diagnosis and Remediation**, Englewood Cliffs, NJ Prentice-Hall, 1982.

Campbell, B., & Baldwin, V. (Eds.) **Severely Handicapped-Hearing Impaired Students: Strengthening Service Delivery**. Baltimore: Paul H. Brooks, 1982.

Education Committee News and Views

by Betty Pendler, Chairperson

by Betty Pendler, Chairperson

Parents and Professionals recently came together at a highly successful workshop in Syracuse, which was coordinated by Thomas Scholl, a member of our Education Committee. This workshop was unique in that it had the cooperation of a variety of other agencies who helped make it the success that it was: Onondaga Chapter of NYSARC, Onondaga Chapter of United Cerebral Palsy, The Center on Human Policy of Syracuse University, Direction Services of Onondaga County, The North Syracuse Central School District, The Sequin Community Services of the Syracuse Developmental Center, the Vito Giola School of the Syracuse Developmental Center, Transitional Living Service and the Setric Center of Onondaga-Madison County BOCES.

From Professionals: "I feel stronger about supporting parents as advocates for their children after this workshop. Positive aspect: 'The presence of parents who have had experiences advocating for their children was encouraging; I see the need to work more closely with parents.'"

From an administrator: "It gave us experience in reacting to and planning support groups — solid advice provided on how to assert oneself and goals to work toward — imparted good knowledge of school system."

From parents and teachers: "I loved all the material I got to take home and pass on to others who weren't lucky enough to be there. It was great having the combination of parents and professionals to speak to us."

YOU SEE WHY WE SAY THIS WAS A SUCCESSFUL WORKSHOP?

The morning was packed full of information on parent advocacy — how parents and professionals view each other; advocacy in private; public and residential settings, followed by two afternoon workshops covering training parents in attending the "Committing of the Handicap" meeting, and the other, addressing the needs of parents and advocates of children residing in developmental centers. Our thanks to all who attended, and we know with the load of literature they went home with, packed full of information, they had made the day worthwhile.

SENATOR LOWELL WEICKER heard about NYSARC when Betty Pendler attended a workshop in Washington, D.C. on parent advocacy. He urged everyone to be on the alert and watch for efforts to continue to de-regulate in an attempt to weaken PL 94-142. He urges continuous pressures on your respective legislators to remind them not to let this happen.

STATE EDUCATION DEPT. LISTENS TO US. We are constantly reading all the literature and searching for ways to make life easier for the parents. In reviewing the latest pamphlet put out by the State Education Dept. called "Knowing about Special Education - To Help You Help Your Child" Judy Shalvey, one of our members, noted that information for the parent was placed at the very end so we wrote to the Head of Program Development: "My one objection is that although it states at the very end of the pamphlet that parents may obtain copies of their child's record — this should be included as early as page 3 — in the section when the parent meets with the COH. How can a parent effectively plan with the COH if she does not have the same information — test results etc. — to read as the other members have before them? Should there be inaccuracies in the records which only a parent could clarify that is the time for her to change it. So, we told the Office of So, we told the Office of Children with Handicapping Conditions that while we like their publication on the whole, we felt the above information was vital — and we

quote their reply, "We appreciate your suggestion regarding the wording to be placed on page 3 in our new parent pamphlet submitted to you by your committee member Judy Shalvey. We will be revising the wording on that page for our next reprint." These are the little victories that help us surge forth to bigger ones.

Chapter Activities— It is heartening to hear about the chapters holding membership meetings on the subject of education — as well as noting that some chapters are holding workshops in cooperation with other groups. Please keep the Education Committee informed when this happens in your chapter, to feed our ego, and to give us ideas!! Warren Washington, Westchester, Clinton, Delaware and Broome Tioga all had excellent programs — and we know there are lots more out there who have done it — so won't you tell us about it?

The Education Committee finds that reaching out into the community and letting them know that your Chapter is ready and willing to disseminate information regarding the public school system will get you new members — so reach out to early childhood programs, day care programs, head start centers, your local school district, your local special education departments in the colleges — and all those other groups in your community. The Education Committee stands ready and willing to assist you with materials, etc.

MATERIALS AVAILABLE FROM STATE EDUCATION DEPARTMENT

The following new publications are available from:

The University of the State of New York
State Education Department
Office For Education of Children with Handicapping Conditions
Albany, New York 12234

"Special Education for Handicapped Children, Birth to Five," (May, 1982)

"Performance Levels and Individual Needs," (June 1982)

"The Role of An Administrator In the Education of Pupils with Handicapping Conditions" (June 1982)

"Alternative Testing Techniques for Pupils with Handicapping Conditions" (March, 1982)

"Placement and Education of Children with Handicapping Conditions In Private, State-Operated and State-Supported Schools" (January, 1982)

"The Role of A School Board Member in Education of Children with Handicapping Conditions"

"Knowing about Special Education, To Help You Help Your child"

"Your Child's Right To An Education"

"Questions and Answers About Serving the Educationally Handicapped in New York State"

a. "Special Edition, The Institution Schools Act"

b. "Number 1, What Is Special Education"

c. "Number 2, Referral, Evaluation and the Development of the IEP - Phase I"

ACTION ALERT!

PRIVATE SCHOOL PLACEMENT RIGHTS TO DUE PROCESS THE PROCESS FOR PLACEMENT

When the Committee on the Handicapped, after evaluating a child, feels that there is no appropriate program either in their own district, a neighboring district, or in a BOCES program, and recommends to the Board of Education a private day or residential program, and the Board of Education agrees (along with the parents), the Board must apply to the Commissioner of Education for per-

mission to make this placement. The form used to apply is called the PHC (Pupil With Handicapping Condition). The Education Law very clearly states that when a private program is being recommended, the Commissioner of education must approve. In actuality, it is the Regional Associate in the area in which the child lives, that acts on behalf of the Commissioner, in approving or in disapproving this placement.

THE PROBLEM AS SEEN BY THE EDUCATION COMMITTEE

When the REGIONAL Associate disapproves the PHC application made by the Board of Education, there is nothing in the current regulations that allows for an impartial hearing.

THE SOLUTION AS SEEN BY THE EDUCATION COMMITTEE

In order to ensure that due process is provided in this instance, the Regents are being asked to consider an amendment to the regulations which states that "if the Commissioner declines to approve an application for placement of a handicapped pupil in an approved private educational facility, the parent may within ten days of receipt of notice of such determination, file with the department a written request for a hearing before an impartial hearing officer who will be designated by the department. The procedures relating to notice and review of a refusal of State approval shall be comparable to those set forth in subdivisions (b) and (c) of Section 200.5 of this part, and shall be provided by the Education Department. Review of the determination of the hearing officer shall be available by means of a proceeding pursuant to Article 78 of the Civil Practice Law and Rules, and may be instituted by any party to the hearing."

OECHC TO DEVELOP SERVICE DELIVERY SYSTEM FOR THE SEVERELY PROFOUNDLY HANDICAPPED

The following article appeared in the November, 1982 issue of "News Briefs", published by the Office for Education of Children with Handicapping Conditions, of the State Education Department:

"The Office for Education of Children with Handicapping Conditions, Division of Program Development, has been awarded a three-year Federal contract to study and design an improved statewide service delivery system for severely handicapped persons, ages - 21. The purpose of this contract is to establish a system to provide a wide range of essential services to individuals with the following handicapping conditions: Severely Mentally Retarded, Severely Physically Handicapped including Health Impaired, Severely Emotionally Disturbed, Autistic, Blind, Deaf, Deaf-Blind, Multiply Handicapped. Due to the intensity of their physical, mental, or emotional problems, or a combination of such problems, severely handicapped individuals may need educational, social, psychological or medical services beyond those which are traditionally offered by regular and special educational programs. While such persons may currently be served through a variety of public and private service providers under the jurisdiction of several State agencies, there is a recognized need to establish a model for the coordination of these efforts on behalf of those to be served.

The intent of the project initially is to describe and analyze the current system for the delivery of special education, related programs and services for this population. Subsequent activities will involve designing a delivery system and testing key elements of the design in various areas of the State."

The OECHC invites all who have an interest in the provision of services to severely handicapped children and youth to submit written commentary on the strengths and weaknesses of the States current system for providing these services, to Division of Program Development, Education Building, Albany, New York, 12234.

SUGGESTED REFERENCES ON EARLY CHILDHOOD EDUCATION

Cansler, Dorothy (ed.), **Programs for Parents of Preschoolers: Chapel Hill Training Out Reach Project**, Lincoln Center, Chapel Hill, NC 27514, 1978.

Piazza, Robert, Rothman, Roz, **Reading In Special Education, For Preschool Education for the Handicapped**, Special Learning Corporation, 42 Boston Post Road, Guilford, CT, 1979.

Sceiber, Barbara, **One Step At A Time, Closer Look**; Box 1492, Washington, D.C. 20031. A Handbook for Parents.

Programs for Atypical Infants and Their Families, United Cerebral Palsy Associations, Inc.; 66 East 34th Street, New York, New York, 10016, 1977. Series of Monographs Available.

Early Intervention Services To Disabled Children (Birth to Five) New York State Council on Children and Families, Albany, New York, 1981.

Handicapped Children's Early Education Program, Office of Special Education, 400 Maryland Ave., S.W., Washington, D.C. 20202, 1981.

A NEW FUNDRAISE FOR YOUR CHAPTER...SELL SUBSCRIPTIONS TO THE EXCEPTIONAL PARENT MAGAZINE.

This magazine continues to be one of the leading publications, full of information, with articles written by parents and professionals. Your Chapter can take advantage of their fund raising offer by selling subscriptions to this useful publication. Your Chapter gets to keep part of the total subscription cost of \$16.00. Contact Dr. Stanley Klein, Exceptional Parent Magazine, 296 Boylston Street, Boston, MA 02116 for particulars.

EDULETTER — Continues to be published 3-4 times a year with valuable information. We welcome items of interest from all. Kindly return coupon below if you are not already on our mailing list.

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

NAME _____
ADDRESS _____
TEL. NO. _____

CHAPTER AFFILIATION _____

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

Return to:
Betty Pendler, Chairperson
Education Committee
N.Y. State Association for Retarded Children, Inc.
393 Delaware Avenue
Delmar, New York 12054

PUBLIC INFORMATION COMMITTEE

12 Ways You Can Help

OUR COMPLIMENTS TO GENE ALLEN,
Editor of ONEIDA CHAPTER
"HIGHLIGHT"
FOR A NEWSLETTER PROMOTION
IDEA

12 WAYS YOU CAN HELP

ARC
BUILD A RAINBOW

1. **BECOME A MEMBER!** There's a lot going on at ARC & an information membership is vitally important. You'll find news about current issues and future plans in the ARC newsletter, Highlights. Contact Development Office.
2. **RECRUIT NEW MEMBERS!** Although we'd like all members to be active, there is no obligation placed on members, except the modest annual membership fee. (And, don't forget to think about converting your own membership from annual to life.)
3. **INCLUDE ARC IN YOUR ESTATE PLANNING!** New tax legislation makes it imperative for many to review their wills — a good time to include a bequest to ARC. Don't forget to use our legal name: Association for Retarded Children, Inc.; Oneida County Chapter.
4. **DONATE MERCHANDISE!** our thrift shop can sell just about anything — and you receive a tax deduction. Call our thrift shop at 735-6477 for details.
5. **PROVIDE A PERMANENT COMMEMORATION!** A major contribution can be memorialized by rooms and sections which are available for commemoration. More information from development office.
6. **MARK A HAPPY OCCASION!** Or in times of sadness give a remembrance for the family. Tasteful acknowledgements are mailed promptly, without mention of the amount. Forms are available at the reception area or the development office.
7. **TAKE FULL TAX ADVANTAGE!** Use appreciated securities when making a contribution to ARC. The gift of stocks or bonds, which have grown in value, gives you a deduction of the total dollar worth when contributed directly, rather than giving the proceeds of a sale which involves taxable capital gains.
8. **PATRONIZE OUR THRIFT STORE!** Staffed by volunteers from our ladies auxiliary, over \$12,000 is donated annually to the ARC operating budget.
9. **ATTEND OUR CHAPTER FUND RAISERS!** They're fun and all proceeds help ARC directly.
10. **BECOME ACTIVE AS AN ARC VOLUNTEER!** Be a friend to an ARC client or help with an ARC fundraising event — call the development office for details.
11. **RECOMMEND OUR SHELTERED WORKSHOP!** Progress Industries does all kinds of contract work. They need the work and do a top notch job. Call the marketing office for production help and price quotes.
12. **PASS THESE SUGGESTIONS ALONG TO A FRIEND!**



Sub committee on legislation takes a coffee break. From left: Ellen Owens, Henrietta Messier, Chairperson Ellie Pattison, Shirley Valachovic, Betty Pendler.

Legal services for residents of N.Y.S. M.H. facilities

The Mental Health Information Service is a State agency under the jurisdiction of the Appellate Division of the Supreme Court, State of New York, which represents residents and patients residing in developmental centers, intermediate care facilities, community residences, residential schools and psychiatric centers throughout New York State.

In the mental retardation area, in addition to representation about continued institutionalization, the attorney provides representation to clients with respect to community placement, education issues, and Willowbrook Consent Decree compliance. In these areas, the attorney is responsible for the investigation of abuse and mistreatment and is entitled to view records and interview staff.

Attorneys of the Mental Health In-

formation Service are stationed at State facilities and private hospitals throughout New York State and routinely interview patients, attend client related meetings, incident review committee meetings as well as meetings of the Board of Visitors of State facilities.

The powers of the Mental Health Information Service are delineated in 29.09 of the New York State Mental Hygiene Law and are amplified by the Rules of the Presiding Justice of each Appellate Division. Residents, patients, and their families are notified of the existence of Mental Health Information Service by language contained within the admission papers to facilities.

Should questions arise in your area, call your local Developmental Center for information.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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