

Our Children's Voice

Retarded Children Can Be Helped

Vol. XXIX No. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

June 1977



Residence Dedicated

This was the happy ribbon cutting scene at the recent dedication of the AHRC operated Melvin W. Kraus Residence, 224 East 5th Street, Manhattan's first hostel for the severely retarded. Shown (l. to r.) are James P. Murphy, AHRC president; Anne Kraus, AHRC Director of Volunteer Services; State Senator William Conklin of Brooklyn, who delivered the dedication address, and Thomas Coughlin, Deputy Commissioner of the New York State Department of Mental Hygiene. More than 300 AHRC members and guests turned out for the dedication of the facility in memory of Anne and Walter Kraus' retarded son who died in 1975. The residence accommodates fourteen clients.

Governor's plan protested

3 offices proposed

Admitting the Department of Mental Hygiene cannot function as now structured, the Governor's reorganization plan (and no one knows really who the author of the plan is, although it is unofficially attributed to Dr. Kevin M. Cahill, Governor Carey's unsalaried and unofficial health czar), creates three "autonomous" parts in the Department of Mental Hygiene. These would be:

— The Office of Mental Health responsible for treatment and rehabilitation of the mentally ill.

— The Office of Developmental Disabilities (the second version of this measure now calls it the Office of Mental Retardation and Developmental Disabilities) would assume responsibility for all programs for the mentally retarded and those afflicted with other developmental disabilities, such as cerebral palsy.

— The Office of Alcoholism and Substance Abuse, to be created by merging the present Division of Alcoholism of DMH with the independent Office of Drug Abuse Services.

Because new departments can only be created by amending the State Constitution, the three new organizations would technically be called "Offices".

Because the State Constitution calls for a commissioner of mental hygiene and requires him to perform certain duties, under the Governor's plan there will be

three commissioners: one for mental health, one for developmental disabilities, and one for alcoholism and substance abuse.

The three of them acting in concert will "collegiately" constitute the Commissioner of Mental Hygiene referred to in the Constitution, a spokesman for Governor Carey said.

As a practical matter, it means the mental hospitals, schools for the retarded and programs for alcoholism, now all operated by one state department, would, after reorganization, be split along functional lines.

Left unclear, however, in the Governor's proposal, is the question of what would happen when the three new commissioners, labeled now the "Troika", "acting collegiately", fail to agree on a decision in matters affecting more than one of the offices.

At hearings held by the committees chaired by Senator Padavan in the Senate and Assemblywoman Connelly, this proposal met with less than enthusiastic response.

"The plan was drafted without any consultation of any kind with representatives of the 600,000 mentally retarded whose lives the Governor seeks to affect", said Joseph Weingold, Executive Director, NYS-ARC, at one of the legislative hearings.

50 Senators back Conklin

MR-DD office bill introduced

Kremer brings bill to Assembly

Taking the Governor at his word in his Message to the Legislature when he stated, "I believe the time is appropriate to consider the establishment of two new independent agencies: an Office for Developmental Disabilities and an Office for Alcoholism and Substance Abuse", Senator William T. Conklin (R-Kings) and Assemblyman Arthur J. Kremer (D-Nassau) introduced a bill to create an Office of Developmental Disabilities and Mental Retardation in the Executive Department. (S 2990 A Assembly 6691A).

This bill is almost identical to the one passed in 1975 and vetoed by the Governor after his well publicized promise to sign it.

In a statement issued jointly by Senator William T. Conklin and Assemblyman Irwin J. Landes in 1976 when a similar bill was introduced, it was pointed out Governor Carey, in vetoing the bill, cited his own efforts to reform the "broken down bureaucracy" of the Department of Mental Hygiene. He suggested compliance with the Willowbrook Decree would alleviate many of the problems for which parents of the developmentally disabled have sought relief.

As we all know, this has not happened. We are still faced today, according to Senator Conklin, with a situation in which about \$25 million of a \$1 billion budget is allocated to the 97 per cent of the mentally retarded in the community, leaving them certainly meagerly served.

"The Department of Mental Hygiene continues to be unable to break out of the confines of the psychiatric - institution model which has consistently prevented fulfillment of community - based care to all the developmentally disabled", said Senator Conklin. The Governor's statement concerning the creation of a separate office certainly seems to support the contention of the Association for Retarded Children and that of Senator Conklin and Assemblyman Kremer that the time has come for this separation. It has been discussed long enough.

Seemingly to counter the Conklin-Kremer proposal, the Governor's office has drafted a proposed piece of legislation for the reorganization of the Department of Mental Hygiene which is reported and commented upon in a separate article on this page.

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"There isn't a single substantive change for services in the whole reorganization that will lead to a different or better delivery of services in the community."

"What this department needs is surgery, not cosmetic surgery, but radical surgery," he continued.

"What the Governor is trying to do here is to remove a badly infected appendix, it is true, but he is attaching it to the gallbladder. If anything, this is worse than what was before."

A major objection from others is that the Office of Mental Retardation and Developmental Disabilities will remain in the Mental Hygiene Law and continue to be subject to a law which is psychiatrically, rather than developmentally, oriented.

The Rev. Peter Young, a Catholic priest who runs a parish in Albany's skid row, and is a member of the State Council on Alcoholism, expressed unhappiness with the Department of Mental Hygiene. He voiced objection at the proposed merger with the Office of Drug Abuse Services. In addition, the State Conference of County Mental Health Directors, the local officials whose programs must mesh with those of the Department of Mental Hygiene, adopted a resolution, at a recent meeting, unanimously opposing the Governor's plan.

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Book Review

REVOLT OF THE IDIOTS

Blatt, Burton. *Revolt of the Idiots* Glen Ridge, N.J.: Exceptional Press, 1976. 253 pp.

"This is a work of fiction" quotes the author in his prologue. But he continues, "fiction may best portray certain strange truths".

The story tells of a revolt, peaceful yet dramatic in its impact, of the inmates of an upstate New York institution for the mentally retarded. The revolt is led by Adam Mack, an inmate, whose IQ is

"normal" but who, at an early age, was labeled retarded. The story is told realistically, savagely, brutally by means of diary entries, poetry and narrative.

Blatt does not mince words. He is at times, wry, cutting, biting. He tells it like it is (or rather as he understands it). As Blatt says, "I tried throughout to write the truth as I understand truth".

Those who read *Revolt of the Idiots* will either love it or hate it. It's that kind of book.

Appointments etc.

KARIN A. BURGESS

Governor Hugh L. Carey recently announced the appointment of Karin A. Burgess of Cortland, to the Mental Hygiene Council of New York State. Mrs. Burgess is a member of the Board of Visitors of the Syracuse Developmental Center, a member of the board of governors of the State Association of Retarded Children, a founder of the Work Activities Center for severely retarded adults in Cortland County and a member of the Executive Committee of the State Association of Community Mental Health Boards. She has been named for a term ending December 31, 1979.

MARC H. BRANDT

Marc N. Brandt, M.S. Ed., Executive Director of the Sullivan County Chapter, has been appointed to the Board of Visitors of Middletown Psychiatric Center. In a letter to Brandt, Executive Director, Joseph T. Weingold congratulated him on his appointment.

JOHN P. BEYNART

John P. Beynart, of Hudson, was named recently by Governor Carey to the Board of Visitors at Oswald D. Heck Developmental Center.

Beynart, a materials manager for V and O Press is a member of the Board of Governors of the New York State Association for Retarded Children, a director of the Columbia County chapter of the association and a member of the county Mental Health, Mental Retardation and Alcoholism Board.

ELLEN N. MAROUN

Mrs. Ellen N. Maroun was re-appointed to the Sunmount Developmental Center Board of Visitors and is serving as its President for the 1977 term. Mrs. Maroun is a member of the Board of Directors of the Franklin County Chapter, a representative of the State Board of Governors and a member of the New York State, A.R.C. Executive Committee.

WINSTON C. HAMILTON

Winston C. Hamilton, also a member of the Board of Directors of the Franklin County Chapter, was re-appointed by the County legislators to serve on the Community Mental Health Board.

Letters to the Editor

GOOD NEWS SHARED

This letter from Stuart E. Greif, Executive Director of the Putnam County Chapter, points out some very significant progress made by the Chapter and shared as "good news" with us and all of you:

Dear Mr. Weingold:

I thought you would be happy to learn we were able to satisfy our County commitment and also pay half of our loan to the Bank of New York.

Our political efforts to effectuate State payment of funds due us and amounting to some \$46,000 as of January 1, 1977 have been successful to some degree. Therefore, we are looking forward to a continued upswing in our day-to-day operations.

I realize that, only too often, New York State A.R.C. learns of only the negative aspects surrounding its chapters. I thought I would take the opportunity to share with you the factors noted above.

I am enclosing copies of an agreement between D.M.H. and New York State Association for Retarded Children, Inc. so the corporate seal may be impressed upon each copy. You will be interested to learn this is a hallmark with regard to the first hostel established in Putnam County.

Thank you for your cooperation and interest in our progress.

Sincerely,
Stuart E. Greif

THANKS FROM S.D.C.

Color My World at Syracuse Developmental Center was reported on in the January issue of *Our Children's Voice*. Here, Dr. George J. Buchholtz, Director of SDC thanks Geraldine Sherwood and YOUTH-ARC for their help.

Dear Ms. Sherwood:

The "Color My World" project here at the Syracuse Developmental Center by your YOUTH ARC was truly an outstanding project. Not only did a number of youth volunteer their time to make life a little better for our clients, but it brought a number of groups together working in harmony.

I hope they enjoyed the project as much as we enjoyed having them here.

You should be very proud of this group. If they ever need a recommendation from us, please do not hesitate to call.

Thank you very much for all you have done.

Yours truly,
George J. Buchholtz, M.C.

Subsidy correction

In the last issue of OCV we reported that parents who bring their children home from institutions other than Willowbrook do not get the "family caretaker allowance".

It has been brought to our attention by the parent of a resident at Letchworth Village that this is not so. This parent will receive a family care allowance when she takes her child home from Letchworth Village.

MH budget penalizes community retarded

Dollar increase "Illusory"

Although the legislative appropriation of \$934,531,200 for mental hygiene is \$4.1/2 million more than the Governor's request, and \$21 million more than the 1976-1977 budget, this is illusory in terms of services to the mentally retarded. The fact is \$13 million of this is appropriated for alcoholism services in the Department of Mental Hygiene.

In the Governor's budget request to the legislature he stated, "Because of the serious fiscal constraints from both the state and its localities, no increases have been recommended for program expansion, inflation or annualization" in the local services budget.

This promise the Governor has kept.

Thus the amount of about \$15,200,000 for local services for mental retardation remains the same. The apparent increase of about \$1,800,000 goes for Chapter 620 services for those who have been deinstitutionalized. Not a cent of it is earmarked for those who have remained in the community. There are some positive aspects to this budget if they will be extended to those who have not been institutionalized. For example, there is \$3,400,000 for Purchase of Service Contracts directly by the Department of Mental Hygiene from the community agencies. This, however is being used primarily for the Purchase of Services for deinstitutionalized residents or for day services for those who remain on a resident basis in the institutions. It is hoped Commissioner Coughlin's attempts to broaden this to services for those in the community as well will be successful.

The Governor also recommended, and it has been adopted, that there be about \$9 1/2 million to support community residences for the retarded. These funds also include provision for the creation of 1000 new community residence beds, 500 of which, however, must be for residents placed in the community from the institution, in spite of the fact that 97 per cent of the mentally retarded are in the community, and less than 3 per cent are in the institutions.

For better or for worse, the legislature has eliminated the Office of Citizens Participation and the Office of Social Rehabilitation. In addition, for the second year, the legislature has refused the Governor's request to enable the Commissioner of Mental Hygiene to transfer

funds from State Purposes to Local Assistance.

There is no suggestion in this budget, or anywhere else, that we can see (except from legislation supporting the program of the ARC), to change the formula of state support for local services being rendered by agencies such as ours. The quite shocking effect of the present formula is clearly demonstrated by another article in this issue describing how local government is using its tax funds, starving mental retardation while feeding mental illness programs. On balance, according to an Association spokesman, this is a most disappointing budget.

Even if one were to agree with the Governor's thrust that major effort should be on the placement of the 2300 mentally retarded persons from the institutions back to the communities during 1977-1978, we must pay attention to Dr. Kolb's testimony before the State Legislative fiscal committees that this would be "very difficult", citing community resentment, housing codes for group homes, and the delays in setting up new programs in some of the problem areas.

These are addressed in bills introduced at the request of the Association such as the zoning bill, (Conklin - Gotfried). But we see little support from the administration.

MR advocacy

pamphlet available

Three pamphlets dealing with advocacy for the mentally retarded have been produced by the staff of SOAR and are now available from the Office of the State Association.

The three pamphlets are divided into these subjects:

1. Community Organization
2. Strategies for Problem Solving
3. Public Relations

These three together would be a valuable addition to advocates, parents, professionals and anyone dealing with the problems of mental retardation in the community or elsewhere.

The three pamphlets are sold together. The price is \$5.00, including postage and handling.

Our Children's Voice

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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

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Special Ed not "charity"

At the invitation of William A. Hart, district superintendent, Dr. Bobbi Kamil held board members, special education teachers, administrators and representatives of private agencies spell-bound recently at conferences in Canton, Potsdam and Massena schools as she explained the difficulties the State Education Department has when writing legislation for school districts on the education of the handicapped.

Emerging from the three conferences was the new role of the state Education Department to insure that such education does take place in every school district. (In St. Lawrence County some districts have not yet professionally identified their handicapped students.)

SPECIAL PROGRAMS OFTEN NOT HELD

After identification of such students, state aid money may then be requested for programs for the handicapped. For many years, although such programs were mandated by law, school districts excused themselves from the responsibility by saying they could not afford the programs, Dr. Kamil said. Now the money is available through state aid. Therefore, all new legislation is aimed at establishing the rights of the handicapped child in any situation which comes up for legal interpretation.

This means school districts are no longer protected by law for avoidance of such responsibility; only the child is protected by law.

DISTRICT COMMITTEE NEEDED

The formation of a District Committee on the Handicapped is now recognized as the first step towards identifying such children. The professional members of such a committee then make recommendations to the school board on each handicapped child as to the kind of program necessary. However, such information is coded to protect the child's privacy.

No school district can recommend placing a child in a state school. So, if programs are not quality programs in the school district or BOCES programs, the district must pay for private school education of such children, which can be very expensive.

Martini, friend of retarded, dies

Hundreds of mourners filled St. Ephrem's Roman Catholic Church last Thursday morning to pay their respects at funeral services for Gabriel Martini. They came to pay tribute to a man who had devoted the last 18 years of his life to helping the mentally retarded.

Born and raised in Bay Ridge, Martini was known to everyone in Brooklyn who worked with the retarded. He was regarded as one of the most dedicated individuals in the field. Through his speaking engagements at civic and service clubs throughout the borough, Martini raised thousands of dollars for the Guild for Exceptional Children.

In 1972, Martini was appointed assistant executive director of the Guild for Exceptional Children, a post which he held until his death. He also served as counsel for the Guild, although he was not compensated. From 1972 to 1975, he was the coordinator of the Brooklyn Southwest Mental Retardation Regional Program, and acted as counsel to the New York State Joint Legislative Committee on Retardation.

COMMITTEES ON HANDICAPPED URGED TO SPEARHEAD PROGRAMS

To spare a school district such an expense, which can vary from \$10,000 a year to \$30,000, it is urgent that all schools immediately begin such programs through the Committee on the Handicapped, Dr. Kamil told her audience.

In all litigation in the future, the law will find for the child, Dr. Kamil contended, and the parents of such children must be advised of their role in determining their child's program of education. So what this legislative thrust defines for school board members is that special education is an unalterable part of the curriculum which cannot be voted out at annual meetings but must remain in the budget even though the school is on an austerity budget.

The law establishes once and for all that such programs for the handicapped are not "charity programs", but are a part of the public law which states that every child is entitled to a free public education.

There is no longer a legal medical exclusion for any child unless it can be demonstrated by actual case that the presence of such a child endangers the other children in school.

SCHOOL DISTRICTS MUST ADHERE TO LAW

Many aspects of this education law are destined for litigation, Dr. Kamil said, but school districts must adhere to the law as it is written now until clarifications emerge from the court.

School professionals and private agencies are concerned about the arrival of multiple handicapped children in school districts where no programs are being devised.

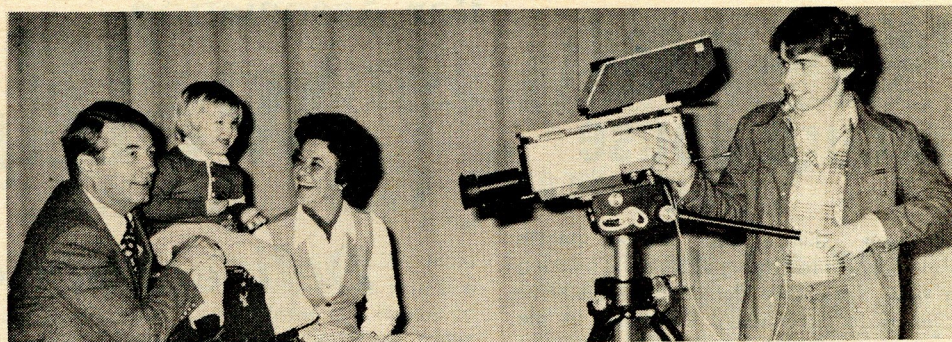
Parents are encouraged to speak out on the subject of preparing the school district and to insist on professional guidance for the legal interpretations of Education Law 853 which mandates appropriate educational services to all handicapped children.

Basic competency tests disputed

In a letter written by a group of concerned parents and supporters to Thomas D. Sheldon, Deputy Commissioner, University of the State of New York in Albany, the Board of Regents requirement that pupils pass basic competency tests in order to be eligible for high school diplomas was strongly objected to.

The specific item in question was a paragraph in a letter that was written by Sheldon in the spring of last year. The paragraph states: "Pupils with Handicapping Conditions. Copies of the Basic Competency Tests will be provided in Braille and in large type for pupils with visual handicaps. For pupils with other physical handicaps, the schools may make the same types of adjustments as would be appropriate for Regents examinations. Special education students may be excused from taking the Basic Competency Test at the discretion of the school, but it will not be possible to waive the high school diploma requirement. Each school district will have the responsibility for developing an adjusted program of study for special education pupils and for developing standards for issuance of an appropriate alternative certificate attesting to completion of such program."

The contention of the parents is that this paragraph limits the flexibility in delivering tests to blind, visually handicapped and physically handicapped children only. They believe that this effectively excludes other handicapped pupils from obtaining high school diplomas. They strongly urged the State



Billy Alsid, ARC pre-schopler, visited the Onondaga Community College Radio and Television department along with John F. X. Mannion, president of Unity Life, sponsors of the second and annual tennis tournament to benefit the ARC. Catherine Stampalia, Chairperson of the department, and camera operator, Bill White, demonstrate the equipment used to videotape the finals of the mixed doubles benefit which netted nearly \$5,000 for the ARC programs.

Tennis tourney for Onondaga

The second annual Unity Life Tennis Tournament raised nearly \$5,000 for the Onondaga County Association for the Retarded this April.

This creative sporting benefit event was the second sponsored by the Unity Mutual Life Insurance Company, which has its home offices in Syracuse.

The theme "Love Enough to Go Around" proved to be such a success last year that it was repeated with double the draw and triple the funds raised for the ARC.

The association was able to raise many new friends through the three-day benefit in addition to raising funds to be used in the Infant Services division.

As Robert J. Horn, president of the Onondaga County Chapter of the New York State Association for Retarded Children, expressed it, "The voluntary financial support from groups and individuals in the community is necessary if we are to continue in our role as advocates to all the retarded in Onondaga County."

The voluntary expressions of "love enough" came not only through the sponsorship of the Unity Life Insurance Company, but through the support of generous gifts of area individuals and companies designated as "Aces" and

"Loves" on the Tennis Program. Their contributions of gifts ranging from \$25 to \$200 in addition to the entry fees of the 80 participating teams demonstrated the expression of concern within the community.

Beyond the direct contributions, the court time and space were donated by the Limestone Tennis Club in Manlius, and refreshments of wine and cheese were donated by area businesses.

The Onondaga Community College Radio and Television Department videotaped the finals of the event for cable television bringing even more attention to the needs of the local ARC as it was televised.

John F. X. Mannion, president of the Unity Mutual Life Insurance Company, expressed his thanks and commented, "The generosity of those who gave of their time and energy to this worthy cause should be an inspiration to us all."

Play was divided into three categories, with 16 teams in the pro category; 32 each in the Amateur A and B and new this year, a consolation round. The ARC-Unity Cup Mixed Doubles is becoming a tradition in upstate New York and each year the winners are the retarded of Onondaga County.

Education Department to immediately revise this highly arbitrary and capricious ruling. This is to make it consistent with the purpose and intent of Chapter 853 of the Education Law.

The parents said this restrictive requirement runs counter to modern thinking on handling problems of handicapped children and also demonstrates a blatant indifference to the needs and rights of the handicapped.

They pointed out that, in approving Chapter 853, Governor Carey stated: "This bill will require every school district to assure that appropriate educational services are provided for each child with a handicapping condition".

"The bill recognizes that education policy affecting children with handicapping conditions should not be made at the local level without participation by parents and guardians".

It is their view that the paragraph in Sheldon's letter was unfair, discriminatory and deprives many handicapped children of their equal protection under New York law.

They pointed out that, at a minimum, those handicapped children who require the services set forth in 4401, subdivision 2 (a) are precluded by this paragraph from obtaining appropriate education services. Diploma denial will be an unbearable stigma for those already burdened with handicapped conditions. They feel there is no reason for it, except perhaps bureaucratic rigidity.

They stated that a more rational and equitable approach on the delivery of the Basic Competency Tests for handicapped children as defined in 4401 can be easily determined. They asked to participate in any further review or evaluation of the matter.

Although they requested a response from Sheldon, to date nothing has been received.

Legislative action

by charities defined

The Federal Tax Reform Act of 1976 includes a section of vital importance for health, welfare and similar organizations that wish to influence legislation on behalf of their clients. Replacing the vague limit of "no substantial activity," the new law give specifics.

For those organizations that elect to do so, beginning in 1977, 20 per cent of the first \$500,000 of their exempt purpose expenditures can be devoted to legislative activity without endangering their tax-exempt status. What's more, 15 per cent of the second \$500,000 plus 10 per cent of the third \$500,000, plus five per cent of any additional sums are permitted — subject to an annual limit of \$1 million.

There is a separate limit on "grass roots" activity (attempts to influence the general public on legislative matters) of one-fourth of the above sums. Penalties are provided for excess activity.

Reform urged to curb abuse

Private citizens and mental health professionals testifying at a public hearing in New York City demanded legislative reforms to curb sharp increases in the number of patient abuse cases involving employees of the State Department of Mental Hygiene.

Members of the State Assembly Subcommittee on Patient Abuse who convened the hearing were advised physical, sexual and psychological abuse of patients had resulted in the dismissal of 115 state workers in the 30 month period since July 1973, but the figure accounted for only one-third of the requested terminations.

The statistics were drawn from a DMH study by Joseph T. Weingold, executive director of the State Association of Retarded Children. He said they revealed "Just the tip of the iceberg." Weingold reported more than half the cases involved physical abuse. He said the remainder included charges of sleeping on the job, abandonment of work stations, sexual abuse and inadequate supervision of patients.

INCIDENTS AT MR CENTERS 4X WORSE THAN ELSEWHERE

Weingold said incidents in developmental centers for the mentally retarded were four times those recorded in psychiatric facilities for children. One of the state's major developmental centers is located in Dutchess County as Wassaic. Weingold alluded to abuse cases there but did not elaborate.

Weingold was one of eight witnesses to testify at hearings chaired by Assemblyman Paul E. Harenberg of Suffolk County. It was the third and final of a series that began last December in Syracuse. No representatives of Mid-Hudson region mental hygiene facilities have testified.

FIRST HEARINGS ON ABUSE

Harenberg said it was the first time statewide hearings had been held on patient abuse and the first time his committee had used subpoena power to bring on reluctant witnesses.

The freshman assemblyman said among those subpoenaed for closed sessions were mental hygiene facility workers who feared reprisals for reporting abuse incidents.

Weingold said it was no secret that employees of the Willowbrook Developmental Center for the mentally retarded used a "reign of terror" against fellow workers who reported abuse cases. He said the tactics included "slashed tires and threats of physical harm".

Witnesses called for tighter psychological screening of employees, better in-service training and legal representation of patients at disciplinary hearings.

James D. Featherstonhaugh, counsel for the Civil Service Employees Association which represents more than 62,000 DMH workers, blamed increased abuse cases on poor working conditions, personnel shortages and low pay.

He said workers may have been reluctant to testify before the subcommittee for fear of reprisal from facility staff members who control their jobs. He complained that facility directors have "dictatorial powers".

Several witnesses said thefts of patient property and pilferage of state owned property were rampant in mental hygiene institutions. One woman testified a truckload of Christmas gifts for patients had disappeared from a loading platform at the Bronx Psychiatric Center.

Bar Association

Weingold on panel

Delivers statement on informed consent

The Committee on Mental Hygiene of the New York State Bar Association held an open meeting early this year in New York City on the topic "Informed Consent in the Care and Treatment of the Mentally Ill and the Mentally Retarded". Joseph T. Weingold, Executive Director, New York State Association for Retarded Children, was one of seven panelists. Simon Rosenzweig, Chairman of the Committee on Mental Hygiene acted as Moderator.

Weingold prepared and delivered a statement on informed consent on the part of the mentally retarded only and related it to the specifics of "placement".

At first glance, it would seem that the very phrase informed consent is tautology. Consent must be given to something in which the supposed consentor must participate either actively or passively. Such consent, it is obvious, cannot be given in vacuo but on the basis of the facts relating to the act to be performed or done. The question, therefore, of the ability of the consentor to understand all the ramifications of agreeing to such an act, is not only important but a sine qua non if such consent is to have any meaning, legally or otherwise.

Since the definition of mental retardation as a condition of subnormal intelligence accompanied with a deficit of adaptive behavior, presupposes to a larger or lesser degree inability to understand the proposal or cope with its consequences, all consents must be hemmed in with safeguards and qualifications to assure the protection of the rights of the person affected.

The situation, in the case of the mentally retarded, that brought the whole question of informed consent to the fore was the placement of such persons in the "least restrictive environment" so often cited by a court but never clearly and absolutely defined.

The haste, one must almost say the obscene haste, of the Department of Mental Hygiene to "deinstitutionalize" persons in the institutions of the Department of Mental Hygiene dealing with the mentally retarded, lead to very obvious abuses of the rights of the residents.

Even though the Mental Hygiene Law requires the absolute consent of the parents for the transfer of minors, (and courts have held even from building to building, let alone from institution to institution), this has been violated in a number of instances by the directors of these institutions. In the case of the adult, however, the law speaks of "informed consent" of the adult. When it became obvious that the Department of Mental Hygiene was beginning to consider transfer from institutions for the mentally retarded to other institutions for the mentally retarded, or even to buildings in psychiatric hospitals as part of the least restrictive environment ploy, the whole question arose of whether, indeed, these residents were consenting to this, and if in fact, there was a written or oral consent; was this consent given with the full knowledge of the person affected of the effects of the action. Further questions were raised as to whether the person affected was represented by anyone, and sometimes they were not, even though there was a legal guardian.

It would seem obvious to anyone working in this field, that least restrictive environment means what it says, "least" not "less". To us working as a voluntary

organization in the field of mental retardation for over 20 years, the least restrictive environment is (a) independent living in one's own apartment or house; (b) living with one's family, (c) failing that, some form of congregate or group living in the community. All of these, note well, are placements in the community, not transfers to other institutions. Under no definition can the transfer from one institution to another or from one building to another, certainly not from an institution for the mentally retarded to an institution for the mentally ill, where no mental illness is involved, be considered "least restrictive".

Although a method of involving the representatives of the residents has evolved through a series of regulations, we find these inadequate, and the results quite astounding. They are inadequate because they presuppose the ability of the representatives of the client to come at any time the Mental Hygiene Department wishes to discuss a placement. It does not provide, on a formal basis, for representation of the client by counsel to be paid for by the Department of Mental Hygiene, if that is considered necessary by the client or his family or his representative.

The astounding results are that many, many of these placements are transfers from one institution to another, or from one building to another, or even into the community without a provision of total services necessary to make a meaningful life for that person.

What kind of information was given that this would result? What kind of consent can be called informed consent when this is the result? What we suggest is that no placement should be permitted under one institution to another except under the most compelling reason. Furthermore, no placement shall be made in the community without the provision of the follow-up services over and above the living quarters and support.

But even in this, should not the resident have a say? How can the resident have a say in this, even through a representative, if all the consequences of the placement are not revealed, not in words, because the cognitive processes of the mentally retarded are something less than what we would want in such a situation, but an actual exposure physically to what is going to happen to the resident, even on a trial basis. Only then, and then only, in our opinion, can you have so-called informed consent. Why shouldn't the same rule of protection of the client obtain in this situation as it would in experimental treatment, or shock treatment, surgery, etc.?

This is not too easy we must admit. To tell a mentally retarded girl or woman that sterilization will mean that she cannot have a baby may be of no meaning to her, but of great consequence to her in her future life. How do you get around this? Certainly, most retarded can understand the word die, and that under certain treatments of an experimental nature they may die. That is easier, but when we get into the subtlety of where you are going to live and what it will mean to you, we must have much more than just talk.

To summarize, it is our opinion, transfers from one institution to another, except in cases to bring clients nearer to

their homes and families, can never be done with informed consent. This transfer may be in the "better interests" of the client, but certainly not in the "best interests" of the client.

With regard to placement in the community in one of the situations described previously, we suggest a period of trial placement before consent is elicited.

At all stages in this game, the client should be represented by adequate counsel, paid for by the state, whether engaged by the client, his parents, or guardian to protect his interests. And, finally, any placement must be put forth in writing with the total plan for those involved, including consent of the providers of the services, and funding clearly delineated.

And then, in the long run, if the client, or his attorney, or his representatives, decides that the client should remain in the institution, what do we do then?

We are dealing here with a whole family constellation. Parents have made the decision sometime ago, some many years ago to divorce themselves of the child's presence either for their benefit, or for the child's or both. Now we come along and say to the parent, this child must go back into your family, or into the community, certainly away from the supposed lifetime protection of the institution. In effect, psychologically, we are asking the parent to go through the whole traumatic experience all over again. Is it any wonder that there is resistance to this? The real astounding fact is that in a field in which psychiatry seeks to be preeminent, this phenomenon is so little understood.

I have deliberately limited myself to a very specific set of facts, because I believe that all the problems that have been set forth, the notice of meeting, and others we can think of can be discussed in seminars for weeks and months.

What I have suggested here is one possible solution for informed consent in a specific situation, only. I am not sure we even can get real "informed consent".

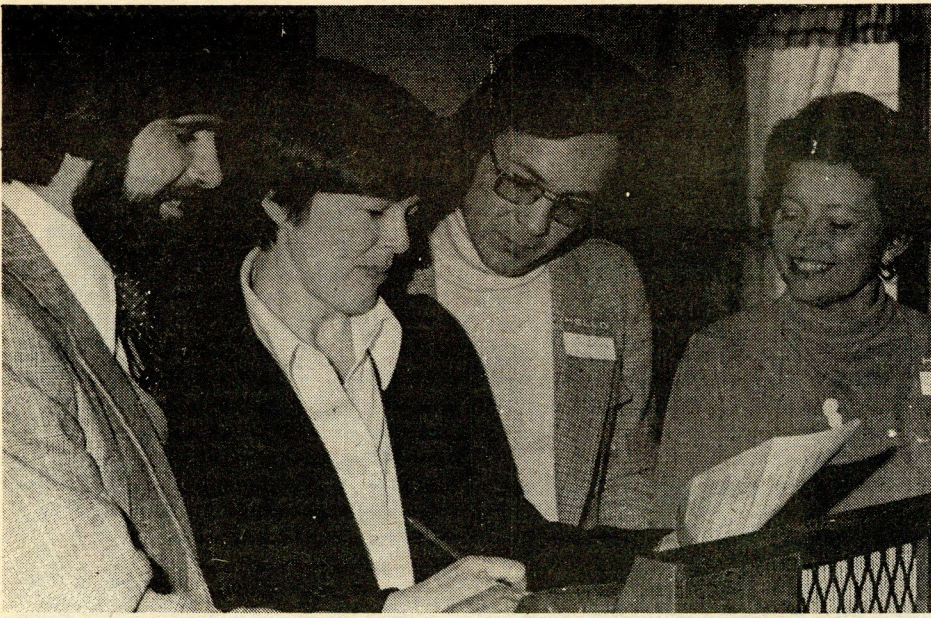
Personal allowance for family care

Family care providers, who provide homes for former patients under a Department of Mental Hygiene program, may now apply for reimbursement of up to \$290 a year spent for personal expenses of their clients. The additional funds have been made available under Chapter 805 of the Laws of 1975. Family care providers can apply for reimbursement through the DMH facility from which their clients were referred.

The new program allows an annual reimbursement for each client of up to \$90 for clothing, up to \$100 for personal requirements and incidental expenses and up to \$100 for recreation and cultural activities. Requests for reimbursement should be fully documented.

HEW recently ruled that the \$290 is generally considered not to be income, which means that the State benefit will not be deducted from the SSI payments which 6500 of the 7500 New York family care clients depend upon.

The State's Family Care program pays providers \$218.70 a month (\$273.70 in New York City) for each client as well as a monthly client personal allowance of \$18.



From left, George M. Heymann, SOAR associate attorney; Marilyn Wessels regional chairperson, Capital district education committee, N.Y.S. A.R.C.; Jim Johnson, northern region chairperson education committee for state ARC and Eleanor Pattison, northeast regional vice president ARC, participate in regional workshop.

ARC conference held

The Northeastern Region of the New York State Association for Retarded Children (ARC) held a day-long workshop on education for the handicapped in Morrisville, New York recently.

The session, conducted in the Sheltered Workshop on the Salmon River Road, featured lectures and discussion on the advocacy role parents and others can play on behalf of the handicapped.

Mrs. Ellie Pattison, regional ARC vice-president and a keynote speaker, outlined state and national legislation increasing the rights and responsibilities of parents of the handicapped, according to a press release.

Mrs. Marilyn Wessels of Schenectady, who organized a Parents Education Committee in her city, described its development and success in making the school board aware of the concerns of parents of handicapped students.

"Significant changes were made gradually," Mrs. Wessel noted. They included in-service courses for teachers, developing school activities and integrating the handicapped with the rest of the student body where possible.

Other afternoon speakers who developed Mrs. Wessel's theme included Mrs. Betty Pendler of New York, chairman of the state ARC education committee; Dr. William Penner, director of special education at Plattsburgh State University College; and Paul Wight, director of special education for the Clinton, Essex and Franklin County BOCES.

Dr. Penner recommended that parents try to evaluate programs by asking to know — and examining — the goals of a program and the specific steps outlined to achieve those goals.

Wight suggested means of judging facilities and staff and discussed the role of volunteers and volunteer training programs.

Mrs. Pendler told the group: "Your child's teacher is your and your child's best friend." She urged parents to visit schools as observers and to question procedures they do not understand.

And she told the parents to have confidence in their judgments about their children's educational programs.

Gladys Delahoy dies recently

Gladys R. Delahoy, a founder and past president of the Chautaugua County Association for Retarded Children died recently in Lakewood, New York. She was presently serving on the Board of Governors for the New York State Association for Retarded Children. Memorials were suggested to be made to the Jamestown Association for Retarded Children in Mrs. Delahoy's memory.

"You know your child better than anyone else and you can evaluate more adequately whether he or she is making progress in his school situation," Mrs. Pendler concluded.

George M. Heymann, ARC associate attorney, outlined the State Handicapped Law of 1976.

Benevolent Society home at Willowbrook

In response to the needs of the residents at Willowbrook Developmental Center, the Benevolent Society for Retarded Children is developing a community residence on the grounds of the Center. Designed to prepare clients for their return to life in the community, this program will be transitional in nature. Formerly used as the Director's house, the proposed residence is now being renovated to comfortably accommodate nine severely retarded adults and two live-in staff members. In addition to an inhouse program encompassing activities of daily living, community orientation and leisure skills, prospective clients will attend community-based day training programs on weekdays and will participate in social and recreational events in the community on weekends and in the evenings. The length of stay for each client will be based on individual needs and the availability of appropriate community residential resources in the respective home borough.

Third residence for Essex

Essex County Chapter of the New York State Association for Retarded Children has opened a third community residence in Port Henry. This residence is operated as three separate "supervised apartments". The facility, formerly known as St. Patrick's Rectory is now called the "Wetherbee Apartments".

The facility has apartments for 14 residents supervised by Resident Managers. All residents attend the Essex County Sheltered Workshop or their own job in the community. There is one apartment for four males and one apartment for four females. The third provides housing for those individuals who need closer supervision. This facility provides housing opportunities for developmentally disabled individuals who are ready for a more independent living situation. This is the final residential training program before an individual lives on his own. Residents have moved in from one of two other facilities operated by the Chapter. One is Port Henry and the other is Ticonderoga.

What does the State Assn. do for me?

January 17, 1977. To plagiarize from President Franklin D. Roosevelt, that is a day that will "live in infamy." It was on that date that the Albany County Chapter of the New York State ARC did not open. It marked the first time in the Association's history, just two weeks short of 28 years, a local ARC closed down because it went "broke."

In the days just preceding this unhappy situation, the Albany County Chapter had been struggling mightily to free itself from a terrible cash flow situation. Saddled with a large loan from a previous administration, the Chapter Board and Executive had spent the year 1976 following up on thousands of dollars in funds due them from various state contracts. Now, their bank loan greatly reduced but still costing them, their assessment for two years unpaid, an emergency loan from the State Association spent, \$9500 in unpaid bills, they found themselves with just enough money left to pay their staff and client payrolls and close the doors.

Almost immediately, all of the State agencies serving the retarded became very concerned, as the closing put almost 100 retarded persons out in the street and without a program. A meeting was called for January 19. Members of the Education Department, Mental Hygiene and Office of Vocational Rehabilitation were all present. Using the iron hand in the velvet glove approach, they shared their concerns, voiced strong support and then told the agency to get to functioning within a few weeks or be closed out as a viable program.

The frustration of an agency was highlighted in this session. One Department representative promised (in good faith, we believe) that he would "walk a voucher through" for us and we'd have money in two weeks. Twelve weeks, to the day, later, we were able to deposit the first funds from that source.

Under pressure to reopen, but without the actual cash to do it, the Chapter turned to the State Association. Assistant Director John Bertrand was on the scene, and after receiving the Chapter's position, suggested a state "receivership" for the Chapter, wherein the State Office would open an account to receive Albany Chapter's funds and disburse its payables, using funds of the State Association to assure a cash balance in the account, and with State Association officials signing all checks. The Chapter Board agreed to the procedure, and State Executive Director Joseph T. Weingold and President George G. Hirsch quickly agreed to this approach and obtained Executive Committee approval for same.

Within 3 weeks, all services were again in place, and the Agency was back in business. Were it not for the State Association, however, this could not be the case, as through March, Albany ARC had expended over \$80,000, and had seen only \$8,500 of State reimbursement, that an advance from Developmental Disabilities.

Albany President Frank Sheridan, spoke for the entire Chapter when he recognized that Albany County Chapter "is not yet out of the woods, but we are ready to stand as an example of an answer to the question, 'What does the State Association do for me?'"

Handicapped count low

States may lose Federal funds

The national count of handicapped children has turned up far short of what was expected. As a result, states may lose some already appropriated federal money.

U.S. Office of Education (USOE) officials are both puzzled and dismayed by the figures. At least 4.5 million handicapped students were expected to be counted. But the actual count appears to be about 1 million less than that. While the total count was predicted to be about 10 per cent of the school population, the actual one is running at 7 to 8 per cent. When Congress passed the Education for All Handicapped Children Act in 1975, the standard estimate was that there were 8 million handicapped children in the United States.

Because the formula is based on the number of children being served, federal money for states and school districts in the next school year depends on an average of two counts in this school year. The counts do not appear to be high enough this year to justify all of the \$315 million advance funding for the coming school years.

Explanations for the low count range from timing of the October 1st count as being "too early in the school year" to differing definitions of "handicapped". For example, although Federal regulations exclude "socially maladjusted" children, many states provide special education for these children.

In passing the handicapped law, Congress stressed states must search out

unserved children. Although USOE funded a media campaign to make parents aware of their handicapped child's right to an education, not many unserved children have been found in the search. It is possible, therefore, that Congress and USOE's Bureau of Education for the Handicapped (BEH) have made a massive miscalculation of the true number of handicapped children.

Education groups, however, will fight to hold the already appropriated funds for the handicapped. Although every survey shows states need more money for special education, \$90 million of fiscal 1977 state handicapped funds are still held by USOE.

William Wilken of the National Conference of State Legislatures, an expert on state financing of special education, points out the handicapped law, unlike many federal programs, doesn't provide high start-up funds. Instead, it increases funds gradually through 1982. States must meet the full service goals by next fall. "Right now", he says, "every dollar is desperately needed out there".

\$57.10 daily for M.R. care

A new schedule of fees for services by facilities of the New York State Department of Mental Hygiene sets \$57.10 per day as the fee for residents in the facilities for the mentally retarded. This fee is to be charged for services, care, maintenance and treatment.

Court decisions affect retarded

Among recent court decisions affecting the retarded are a court's refusal to dismiss a treatment claim against New York officials, a ruling expanding education rights for handicapped and a ruling against the Federal wage law. In a suit under Section 504, a mentally retarded youth, excluded because of his handicap, asks a Federal court to provide a suitable education program.

PLAINTIFFS FAIR WELL IN WOE SUIT

A Federal Court in Brooklyn, New York has refused to dismiss a claim that involuntarily committed patients are constitutionally entitled to, and are being denied, adequate care in New York State mental hospitals. *Woe v. Mathews*, 408 F. Supp. 419 (E.D. N.Y. 1976).

The *Woe* suit is a class action on behalf of all persons between the ages of 21 and 65 who are, or may, be involuntarily committed to State hospitals in New York. It alleges, among other things, that persons committed against their will are sent to State institutions, where they do not receive adequate treatment, while voluntary patients may go to psychiatric wards of general hospitals, where the treatment is adequate. Such disposition of involuntary patients violates their rights under the equal protection and due process clauses of the Fourteenth Amendment, according to the *Woe* plaintiffs. The State does not have to care for mentally ill persons at all, said the court, citing *Dandridge v. Williams*, 397 U.S. 471 (1970), but having chosen to do so, it must treat them in an even-handed manner. Moreover, said the court, involuntary commitment to a mental hospital gives rise to certain rights, such as the right to humane and safe living environment. The court was uncertain about the definition of a "right to treatment", but observed that "purely custodial care must, in almost all instances, be considered inadequate." Thus it refused to dismiss the case, pending a determination as to whether the State had met its constitutional obligations.

EDUCATIONAL RIGHTS EXPANDED

A New York State appellate court has held that the State's duty to educate handicapped children may include payment of tuition for a summer program as well as provision of instruction during the regular school year. In the *Matter of Richard G.* (N.Y. Sup. Ct., App. Div. 2nd Dept., May 17, 1976).

This case involved a ten-year-old child, certified as physically handicapped, who had attended a special summer camp program in July and August of 1974. After a lower court ordered the city of New York to reimburse the family for the summer camp tuition pursuant to State education law, the city appealed.

The Appellate Division upheld the lower court ruling, subject to proof of certain matters upon remand to the trial court. "Where the needs of the child dictate," said the appellate court, "the Family Court has the authority to order that educational services be provided during the months of July and August, as well as during the traditional school year." However, the court said, counsel for the child's family would first have to establish... whether the child in question required educational services during the summer, whether the summer camp provides educational services, whether the goals set for the child in the individual treatment plan were educational or necessary to his education, or whether his education would have regressed had he not participated in the summer program.

The case was sent back for a hearing on these issues.

In another case, a State court ordered reimbursement under State education law, of maintenance costs of a handicapped child in a facility serving mentally disabled children, even though the facility had not been approved as an "educational institution" by the State Education Department. In the *Matter of Tracy Ann Cox*, No. H4721-75 (N.Y. Family Ct., Queens County, April 8, 1976).

"Not all children can be educated as we usually think of the term 'education' — grade school, junior high school, et cetera," said the Family Court. A mentally retarded child, said the court, requires another kind of "education" — how to hold a spoon, feed herself, dress herself, toilet training, et cetera, in addition to speech therapy, psychiatric and psychological treatment, et cetera, — all these and more add up to the education of this and other mentally retarded children, and they are entitled to be so educated. And if (the facility in question) can achieve its goals, and in some measure, improve the child's skills, it surely is worth the efforts of the (facility) staff, and the funds of the City and State.

WAGE LAW RULING MAY AFFECT MENTALLY DISABLED

The U.S. Supreme Court has ruled that the minimum wage and overtime provisions of the 1974 amendments to the Fair Labor Standards Act (29 U.S.C. 201 ff.) cannot be constitutionally applied to State and local governments. *National League of Cities v. Usery*, No. 74-878-879 (June 24, 1976), 44 L.W. 4974. In its decision, the court also cast doubt upon the constitutionality of the 1966 amendments to the FLSA, which subjected State hospitals, schools and institutions to the minimum wage laws for the first time and which have been held to apply to patients and residents as well as to regular institutional employees. *Souder v. Brennan*, 367 F. Supp. 808 (D.D.C. 1973).

EXCLUDED STUDENT BRINGS SUIT

A mentally retarded youth, allegedly excluded from the public schools because of his handicap, has invoked section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794) in asking a Federal court to require provision of a suitable educational program. *Davis v. Wynne*, No. CV-176-44 (S.D. Ga. filed March 23, 1976).

The plaintiff, a 17 year-old who has been classified as educably mentally retarded was a student in regular classes in the Burke County, Georgia, school system through the ninth grade. He was held back in the ninth grade because of inability to do the work, and after a psychological evaluation, was assigned to a special education class for the last 34 days of his second ninth-grade year. For the next two years, however, he was assigned to a regular tenth-grade class. In November, 1975, he was expelled for disruptive behavior which, the complaint alleges, "was the direct proximate and necessary result of his placement into an educational program that was far beyond his mental abilities and which enveloped him in continuous failure."

The complaint alleges that the failure of the defendant public school officials to provide the plaintiff with educational services suited to his needs, and their exclusion of him from the school system, violated section 504 of the Rehabilitation Act of 1973 and the equal protection clause of the Fourteenth Amendment. They seek an order requiring the defendants to provide plaintiff with an appropriate education.



Officials from the St. Lawrence County Chapter, ARC, Richard Laurin and Kate Klein meet with Brenda Clarke from SOAR (System of Advocacy for the Retarded).

St. Lawrence advocacy

With the help of SOAR (System of Advocacy for the Retarded), St. Lawrence County Chapter formed an advocacy committee to support and protect the rights of the retarded.

The chapter was visited by Brenda Clarke, social planning coordinator for SOAR. She toured the ARC facilities throughout the county and spoke at a meeting of the newly formed committee.

"The committee's structure should grow out of the needs of the community", she told Kate Klein, county ARC president, and Richard Laurin, executive director, during a tour of the Ogdensburg sheltered workshop facility.

According to Mrs. Klein, the county committee will function as a local group

and SOAR will act as a "back up" to provide legal and technical support.

Attorney Clarence H. Gratto has been selected as the chairman of the county advocacy committee.

During her tour of the Ogdensburg workshop, Ms. Clarke outlined the functions of SOAR. It provides a forum that can be checked to see that services are being given to the retarded. Taking legal action is "one of the last resorts", she said. She also explained that one of the functions of SOAR is the education and sensitization of the public to the needs of the retarded.

SOAR provides technical assistance to advocacy committees throughout the state.

Califano signs regulations banning discrimination

On Thursday, April 28th, Joseph A. Califano, Secretary of HEW, signed the regulations aimed at banning discrimination against 35 million disabled. This includes 10 million alcoholics and 1½ million drug addicts. The regulations, scheduled to take effect June 1st, will force sweeping changes in employer practices, building designs, and services in schools.

Education of the handicapped must be in public schools, and must be from the ages of 3-21 by 1981. Appropriate education, if in residential schools, shall include good clothing, maintenance, and ordinary medical care.

REHABILITATION ACT PASSED, NOT IMPLEMENTED

Congress passed a Rehabilitation Act banning such discrimination in 1973. But the actual implementation of the Act was left to HEW. It took a lawsuit to force HEW to write the regulations. Although a draft of regulations was prepared and approved by representatives of the handicapped, F. David Matthews, former Secretary, declined to sign the draft and left it over for the new Administration.

Califano had asked for time to review the regulations. But he was under pressure for a decision by the physically handicapped, who followed him through every meeting he has had in the last month and "sitting in" at the San Francisco office for over 20 days.

It is estimated the new regulations will cost recipients of Federal funds \$2.4 billion a year to implement. But not all of this would be new money. Some of that amount is already being spent under other laws. A great deal of that money would be spent by

local school districts, testing and placing 1 million disabled children currently banned from attending public school.

SCOPE INCLUDES EDUCATION AND EMPLOYMENT

The range and vagueness of parts of the regulations which allow exceptions based on "undue hardship" are likely to be the basis of litigation for years. The regulations state that, within 60 days of effective date, all programs not requiring structural changes must be available to handicapped individuals. A political science class, for example, would have to be moved into a building that would accommodate handicapped people. Programs requiring structural changes, such as a science lab, have three years to comply.

Beginning June 1st, employers receiving Federal funds will not be allowed to refuse employment to disabled persons otherwise qualified for the job.

Beginning June 1st, the requirement that parents must contribute to the maintenance of their children in residential centers will be eliminated if those children are minors and a major portion of their treatment includes education.

Employers will not be allowed to inquire about the nature or extent of disabilities before they hire.

The Association for Retarded Children has backed these regulations from the very beginning and joins with the other organizations in urging they be signed. It is a most gratifying step, truly an emancipation proclamation for the handicapped.

Do Nyquist's words match his actions?

State Education Commissioner, Ewald B. Nyquist recently called for greater public involvement in education. In a report to the press he wrote, "The involvement of parents as partners with school officials in the education of their children is a fundamental part of our democratic tradition. The same is true of the involvement of all citizens in the planning and decision-making of their local school boards."

If, the Commissioner asserts, that revitalized, refined, and more open communication among parents, students, education professionals, and other concerned citizens is imperative, it also seems imperative that more parents of handicapped children should be trained and supported to "be involved as partners in the pursuit of what is best for the education of each child."

The Commissioner urges each board of education to take the initiative to implement techniques for involving greater numbers of students, parents, and citizens in the decision-making process.

Although all policies relating to local district affairs must be approved by the Board of Education, Nyquist cautioned boards not to use this as an excuse to avoid actively seeking broad scale input from diverse groups to assist them in the decision-making process. Every board of education should seek out and take all reasonable steps to work effectively with any group in the community which indicates a concern for children and a willingness to support programs to improve their education.

In his report, Nyquist cites many examples of successful citizen involvement nationwide and in New York State.

These are Nyquist's eight principles to help assure successful community involvement. He pledged the Education Department's assistance to local districts undertaking such programs:

1. Involvement should be open to all.
2. Involvement in school affairs should begin at the earliest possible stage.
3. Involvement includes identifying educational needs, setting priorities among them, and developing programs for their implementation.
4. Involvement is likely to be most beneficial when it occurs at, or close to, the level in which educational services are to be provided.
5. Involvement should be carefully planned and implemented.
6. Involvement processes and outcomes should be regularly and systematically evaluated.
7. Involvement will lead to the development of recommendations which should be carefully studied and acted upon by the board of education.
8. Involvement should be carried out through existing organizational arrangements.

The aim of these programs is to help the schools to know and act upon the wants and needs of their students and communities. "More than ever before", he says, "the local school board should seek all reasonable avenues for productive involvement among its various publics".

Why, then, are there not more parents on the committees for the handicapped?

5. Have the authority (and ability) to intervene when help has not been requested by the service recipient.

6. Be capable of training professional and lay volunteer advocates in the skills they need to be effective advocates.

7. Provide information on the rights of developmentally disabled persons to the persons themselves, their families, surrogates and lay advocates, their counsel and other representatives, professionals and public officials.

8. Make the system visible on a statewide basis, including publicizing its services.

The ARC's support of the SOAR system expires on May 31, 1977.

Federal mandate on protection, advocacy

Although the 1975 amendments to the Federal Developmental Disabilities Services and Facilities Construction Act (Public Law 94-103) require the development and implementation in each state, of a system to protect and advocate the rights of developmentally disabled persons, Governor Carey has not yet designated such an agency.

Under the guidelines issued, the New York State Association for Retarded Children is ineligible for this grant because of a possible quote, "conflict of interest." Such an application, however, has been made by Mr. Jack Bernstein, the director of the SOAR program now under the aegis of the Association. His application has been on the Governor's desk for at least 2 months.

The regulations issued by Department of HEW provide that "the Governor shall designate the agency responsible for administering the P & Z system." The regulations further provide that the P & A system will be independent of any agency which provides treatment, services or habilitation to persons with developmental disabilities.

The guidelines state the system must:

1. Be statewide in its impact.
2. Be capable of pursuing legal remedies.
3. Assure the availability of protective services (e.g. appropriate guardianship).
4. Be capable of pursuing administrative and other appropriate remedies.

Four die as house burns

Four mentally retarded persons living with a family in a state-sponsored program in Dexter, New York, apparently panicked when they were awakened by flames. They died in the blaze. The family in whose care they were escaped unharmed.

The four were all former residents of the Sunmount Developmental Center in Tupper Lake and had been living with the family in Dexter in a state program which encourages mentally retarded persons capable of living outside an institution to do so.

IQ Test challenged

Fifteen years ago, the state Senate hired 22 mentally retarded Albany men for work around the Capitol.

With registered IQs (intelligence quotients) of less than 50, the men were thought to be only trainable. Had they registered over 50, they would have been considered educable.

The men did well in their jobs. A few worked in the printing office, a few as messengers. One man became so adept at his printing office job that he was able to take apart and put together printing machines in a single weekend, saving the state significant amounts of money.

The men did so well in their jobs that "somebody suggested we test their IQ again", remembers Senate Deputy Majority Leader William Conklin.

"Well, we got their old records, then tested them again. Every one of the 22 except one tested higher. One boy went from 41 to 69. And here he had been branded as only trainable", Conklin said.

How counties support MR

Recent statewide statistics concerning the contributions of local tax dollars by counties for mental retardation services under the Mental Hygiene Law reveal almost studied starvation of mental retardation in comparison to mental illness.

Statewide, the local tax share for mental illness is 80 per cent of the net mental health budget against 16 per cent for mental retardation and 4 per cent for alcoholism.

Some examples of this support under the Mental Hygiene Law are as follows: In Westchester, the County puts up 96 per cent of local share through tax funds for mental health, but only 3 per cent for mental illness and only \$120,622 on mental retardation. In Ulster, the County spends

"That's when I started fighting against the IQ tests".

Conklin had good reason to question the tests. His own son had been labeled as having an IQ of 49. Today the son has held a job for 12 years and enjoys many of the activities everyone else does. Conklin says his retarded son has saved more money in the bank "than any of my other children".

At a joint legislative fiscal committee hearing on the Department of Mental Hygiene's proposed 1977-78 budget recently, Conklin asked how the department tests people to determine if they are mentally retarded.

He said he was relieved to learn that the IQ test is now only one of a number of tests given to an individual to determine his intelligence level.

What about those 22 Albany men who were labeled as barely trainable?

After 15 years, 17 are still working for the Senate. One is almost ready for retirement. They all have excellent working records, Conklin said.

93 per cent of the local share through tax dollars with only 7 per cent on retardation, \$20,000 against \$272,000. Dutchess, the County spends \$62,000 on mental retardation as compared to \$554,000 on mental illness. Rockland, which is under Unified Services, the County spends \$2,774,000 on mental illness as compared with \$251,585 on mental retardation, and in Nassau, supposedly one of our better Counties, the County spends, of its tax funds, \$5,157,749 on mental illness, and only \$319,625 on mental retardation.

Are there any more questions as to why the New York State Association for Retarded Children wants to get out of the Mental Hygiene Law and rewrite it to produce more equity for the retarded?

ARC protests SSA policy

ARC has written a letter to Commissioner Cardwell expressing its deep concern about a recent change in SSA policy regarding the treatment of wages earned by clients in sheltered workshops for handicapped individuals.

Under the new policy, adopted in May of 1976, SSA considers wages earned by sheltered workshop clients, who are engaged in a rehabilitation program, to be unearned income. Since only the first \$20 of unearned income in any given month is disregarded for SSI purposes, all wage payments in excess of this amount cause a dollar-for-dollar reduction in the individual's SSI check. Prior to adoption of

this policy, sheltered workshop wages were considered earned income and, therefore, under SSA rules, up to \$65 of monthly earnings (in addition to the initial \$20 of earned or unearned income) could be disregarded for purposes of determining SSI eligibility or payment levels.

To further compound the situation, at least one regional office of SSA has interpreted the new policy to mean that the wages of severely handicapped clients in work activities centers also must be treated as unearned income. They argue that such clients are engaged in a structured, goal-oriented "training" program and, therefore, the new policy applies.

Continued from Page 1

In effect, the Carey administration's proposal to reshape the giant mental hygiene bureaucracy amounts to admitting a two-year old mistake. He is now saying that mental retardation and mental illness do not belong together, a concept he rejected in 1975 in a bitter fight with the legislature. Another part says alcoholism and drug treatment programs belong together. The legislature last year refused to approve Carey's request to merge them. The thrust of what the Governor is trying to do for mental retardation is contained in Commissioner Tom Coughlin's statement. Admitting the department now "reflects the medical-psychiatric model rather than the educational-rehabilitation model, better suited to the needs of the mentally retarded and developmentally disabled", he claimed the reorganization would centralize authority in his office. This new office would be upgraded to commissioner

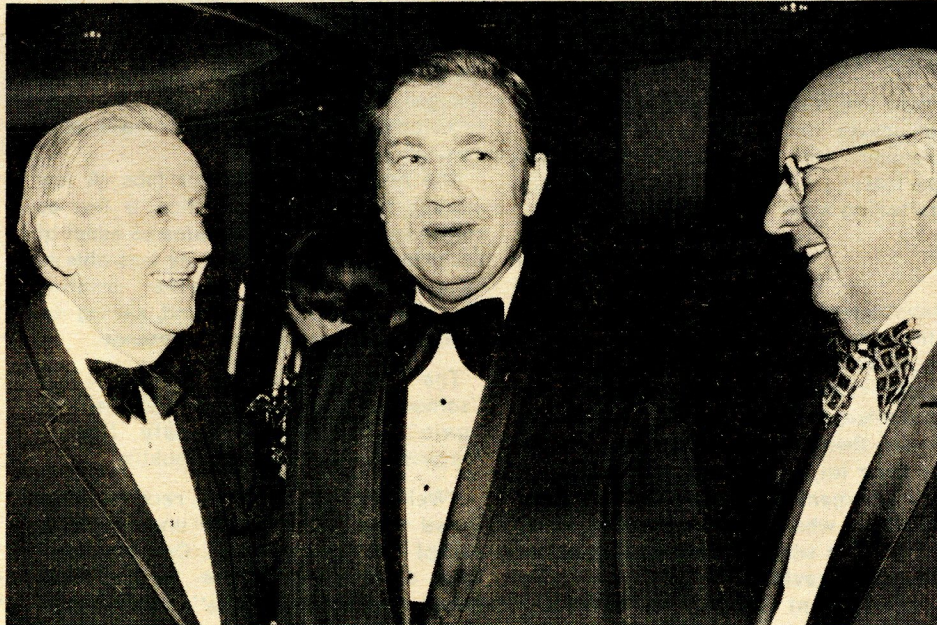
level and would be given full responsibility in such areas as staffing, etc.

The New York State Association for Retarded Children, although cognizant of Commissioner Coughlin's commitment to mental retardation, is convinced this is inadequate if the Office of Mental Retardation and Developmental Disabilities remains in the Mental Hygiene Law. Furthermore, the proposal as presented in its latest form, does not give Coughlin the authority he thinks he is getting. Regulations, supervision, etc. will still be in the hands of the "troika". Mental health boards will still be constituted as they now are with the emphasis almost entirely on mental illness. Regional offices will not be responsive to the needs of the mentally retarded. Indeed, few of them will have staff competent to act in this field. Finally, nothing is changed in the substantive part of the law to give the mentally retarded any hope for future development of community services.

CHAPTER NEWS

What our ch

Leading off Chapter News this issue is our **HERKIMER COUNTY CHAPTER**. They announce that May 8-14 they held their Fifth Annual Swim-a-Thon. This is their biggest fund-raising event of the year and is held in three different locations, on three different days. It sounds like a big undertaking, but we're sure they did well with it. . . . **SCHOHARIE COUNTY CHAPTER** opening their second hostel. Very well done for a small chapter. . . . Speaking of small chapters, we were most interested in the full page article appearing in the Wellsville, N.Y. Reporter, right after the first of the year, giving a full page of coverage to **ALLEGANY COUNTY CHAPTER'S** Tree Workshop. . . . One of the fanciest annual reports we have ever seen is the 25th Anniversary—1976 Annual Report of our **ERIE COUNTY CHAPTER**. Do you think it is because their Workshop has its own print shop that we see such an outstanding publication coming from them? . . . **GREENE COUNTY CHAPTER** working along to maintain their programs under Acting Executive Director, Tom June. Many thanks go from the chapter to the Greene County Liquor Dealers, who sponsored an annual dance for them on March 9th. It is an annual affair and always most successful. . . . A very unusual and pleasant headline coming from **MADISON COUNTY**, where the papers reported that the County Legislature in Madison County made our chapter "quite surprised" and "very pleased" with an increase in the ARC budget for 1977. With so many counties cutting back it was really wonderful to see a county that cared enough about the mentally retarded to do something at this time. Supervisor John S. Patane of the Town of Lenox introduced the resolution and was described by Chapter Executive, Ray Lewandowski, as "tenacious" in his efforts on behalf of the chapter. To him especially, and the other members of the Madison County Legislature, we all say a big thank you. . . . Thanks also to that fabulous **ONONDAGA COUNTY GROUP**, Friends of the Retarded, who once again sponsored the opening night performance of the Ice Follies in Syracuse with the receipts going to the chapter. This, too, has become an annual event, one that means a great deal to Onondaga County Chapter. Thanks also to Unity Mutual Life Insurance Company who sponsored the 2nd annual tennis tournament on behalf of Onondaga County Chapter. Certainly we are grateful for all this kind of help. . . . **SARATOGA COUNTY CHAPTER'S** new Executive Director, Carl Klein, certainly jumped right into a hot bed of activity in Saratoga County. The chapter is working hard toward finally bringing about their long awaited building program and was one of the first upstate counties to get into the purchase of service business with Department of Mental Hygiene. As in **GREENE COUNTY**, the Saratoga County Hotel, Restaurant and Liquor Dealers Association recently ran their second annual charity ball and Saratoga County Chapter was the beneficiary of \$4,500 from that event. . . . Contributions come from many sources and **ONEIDA COUNTY** was no exception. The Utica Jaycees provided \$7,500 to help the chapter acquire their first hostel. If the Jaycees are young men of action, we'll certainly be delighted with that kind of action. . . . On October 25th, **FRANKLIN COUNTY CHAPTER** broke ground for the construction of their first hostel. It is hoped that by the time you receive this, the chapter will have moved into the building. . . . **ULSTER COUNTY CHAPTER** also announced the opening of its first hostel within the past several months and is continuing to work on additional such facilities. . . . **WARREN - WASHINGTON**



Senator John E. Flynn; New York State Assemblyman Gordon Burrows; Eugene Laughery, executive director, Westchester Association for Retarded Children.

Westchester honors Sen. Flynn

Senator John E. Flynn was recognized as "Friend of the Year" by the Westchester County Chapter of the New York State Association for Retarded Children at its seventh annual "Friends of the Retarded" Ball held Saturday evening, March 19th, at the Rye Town Hilton Inn. In presenting the award to Senator Flynn, Mrs. James B. Hosmer, president of the Board of Directors, cited Senator Flynn for his efforts in establishing the WARC Yonkers Training Center and community residences: "He is the exceptional public servant who stays in close touch with his constituency, who listens with compassion to their problems and who responds with all his resources."

Over 300 guests gathered to hear N.Y.S. Assemblyman Gordon Burrows, Master of Ceremonies, and other concerned elected officials, parents and friends as they

pledged renewed efforts to help the retarded. Mr. Daniel Greenwald, president of the Metropolitan Police Conference presented a check for \$2,500 on behalf of his organization. A check for \$24,000, the proceeds of the Fifth Annual Mini-Classic Pro-Am Golf Tourney, was also presented on behalf of the events chairman, Mr. Simon Sheib of Larchmont.

An elegant sculpture of two stainless steel semi-circular columns back to back on a brass base, the work of Sculptor Joseph McDonnell of Bedford Village, was presented to Senator Flynn. The work was entitled, "Proximity" to represent the closeness of Senator Flynn with WARC.

Robert L. Meltzer of Rye Town was the ball chairman. Guests included representatives of other NYS ARC's, also Joseph T. Weingold, executive director of the NYS ARC.

CHAPTER asked us to remember the women of Glens Falls Council 417, United Commercial Travelers of America whose donations from the food and rummage sale provided an AM-FM radio — phonograph for use in the chapter's hostel. . . . Thanks to **MONROE COUNTY CHAPTER** for publishing the contents of our State's opening Legislative Bulletin in full in their neat newsletter. . . . **STEBEN COUNTY'S** newsletter, starting off perhaps sadly but honestly, when discussing their work before the County Legislature. It was all summed up in one sentence which said "to bring you up-to-date on budget matters, we cut our approved budget 10 per cent". Unfortunately this is what is happening in many chapters around the State, but we know Steuben will find some way to provide quality services in spite of these difficulties. . . . You've heard of singing for your supper? Well, the Champlain Valley Chapter of Sweet Adelines, Inc. recently donated a check for \$300 to the **ESSEX COUNTY CHAPTER** to be used to beautify the chapter's Ticonderoga Residence. . . . **SUFFOLK COUNTY CHAPTER** putting their Bohemia Center to work for all sorts of things, recently sponsored the Cornell Manpower Staff Development Program in their new facility. We also enjoyed reading the section in their February newsletter about their T.C. (Total Communication) courses. In these, members of their staff are working with sign language for those clients in need of this type of program. They are running a 15 session course to help parents who might be interested get into this area. . . . From **FULTON COUNTY CHAPTER** comes the following article:

Specifications are being drawn up to be submitted for bid for a 2500 - 3000 sq. ft. addition to the Fulton County Chapter's new facility. The addition was made possible because of funds remaining in the original construction budget and will be used to store items which now occupy space in the sheltered workshop area. The new facility, constructed by the Fulton County Board of Supervisors for the Association for Retarded Children's use, is located on 18 acres of land in the City of Johnstown and exemplifies the outstanding community support which is given to the Fulton County Chapter. . . . Congratulations to **PUTNAM COUNTY CHAPTER** President, Richard Novik who has been elected President of the Brewster Chamber of Commerce. . . . **ROCKLAND COUNTY CHAPTER** struggling with finances, doing their best to find ways to fund needed programs for their clients. It's quite difficult in a county where, in order to change the use of a line item in the budget without increasing the dollar amount, it is necessary to go through nine different levels of bureaucratic approval. . . . **SULLIVAN COUNTY CHAPTER** sponsored an art show for handicapped persons, age 5 to 18. Looked like a very interesting undertaking. The Chapter has selected hostels as their number one priority, and like other chapters, has turned to Bingo as a means of trying to help raise the money. We're sure they're busy planning to host the Association's Annual Convention, October 13-16. . . . We congratulate Dorothy Gasman on her election to the Presidency of **WELFARE LEAGUE - LETCHWORTH VILLAGE**

CHAPTER. Never resting on behalf of the residents of Letchworth Village, the chapter is already busy making plans for their 38th Annual Luncheon for the Fall of 1977. . . . By the time you read this, we expect the **BENEVOLENT SOCIETY**, not to be outdone by its sister chapters, to have concluded its May 14th luncheon, trying to recoup some of the \$12,000 they have laid out of their treasury to help the Workshop Program at Willowbrook. . . . Many thanks to **BROOME - TIOGA CHAPTER**, not only for the fine job they are doing in their own area, but for the fact their Executive Director, Fowler Wilson, and his staff were good enough to share some workshop jobs with our **ALBANY COUNTY CHAPTER**. There is a story elsewhere in OCV about the great difficulties Albany was undergoing and work was badly needed in their workshop. Combining business with business, Broome ARC staff carted materials to Albany while making trips to Legislative Offices for other reasons and helped us keep a number of clients active in the Albany County Chapter. . . . **CORTLAND COUNTY CHAPTER'S** newsletter has become such a handsome sheet, that when I first saw it I thought it was someone else's. It really has done a good job of projecting their image in the community, I am sure, and carries news of Cortland's hard work to get their hostel off the ground. We hope it will be a reality soon. . . . **SCHENECTADY COUNTY CHAPTER** welcomes new Executive Director Chris Hawkinson and we all wish him well, as Schenectady continues trying to provide their excellent services, in spite of serious cutbacks by their County Legislature. . . . **NIAGARA COUNTY CHAPTER**, finally hoping to find a home of their own, and working hard on the development of community residences to go with it. . . . **OTSEGO COUNTY CHAPTER**, now getting out a newsletter on a regular basis. Their November and December issues were sadly filled with news of the budget cuts through which they too suffered like so many other Chapters. However, we were pleased to see that, in March, they were having joint meetings with **CHENANGO COUNTY** through Broome Developmental Center and that Marilyn Wessels, our ever active Education Committee member, was to be their speaker. Marilyn left them all anxious to get out and do more on behalf of the retarded in their area.

Fund raiser



On Saturday, February 5th, a group of SUNY Albany Co. Chapter ARC. In an all day — 24 hour Kappa Delta Sorority of Albany State University approximately \$2,500. Perry Wolfson and J. Wolfson.

are doing and saying for our children.

milestones

League's Silver; Wayne's tenth

Saturday, March 19, Community Wassaic Chapter celebrated its silver anniversary at the Waldorf-Astoria in New York City. Beguiling Pat Collins, Arts and Crafts Council Television, guided the celebration, leading us back 25 years, reliving the news and music of the well remembered days as they rolled by, as the League's accomplishments unfolded in parallel to them.

A number of long cherished friends and family members gathered and addressed nostalgic greetings to the League. Senator John P. O'Day, in his usual engaging style, shared with the guests his memories of the League and his hopes for years to come for the retarded.

The League presented to Richard J. O'Day, Director of the Wassaic Mental Center, a check for \$8,000 to purchase a mini-bus specially equipped to transport wheelchair residents, and to provide them with one means of escape from the world outside the Center's walls.

During this look backward in time and celebration, all 600 in attendance joined in a lively rendition of Auld Lang Syne, and an optimistic promise to meet at the Waldorf to celebrate the League's 50th in 2002!

WAYNE IS 10 YEARS OLD

Wayne County wants to brag a little and let everyone know that they are celebrating 10 years in operation, and that they are not with the same Executive Director, Mrs. Barbara Pyle. Their growth peaks for itself. Ten years ago, Wayne, like other ARC's, in a church building with six children, a director, and a staff. Through the years of growing and achieving, their accomplishments include a new building housed completely in a new public school serving children with an infant program serving from birth to three, modular full day programs, homemakers services, after-school services, and evening recreation programs. They also have a workshop and

albany



way to dollars for the... an, sponsored by the... id raised proceeds of... the top money win-

Vocational Rehabilitation Center, serving not only sheltered employment, but all disabilities, with a projected satellite in the county that should be operating by July. Also community residences have been established. They currently operate two with hoppers, by the end of the year, they will have supervised apartments and additional homes to serve their handicapped people. As extra programs in the community this year, Wayne has established Adult Basic Ed. programs in the evening for the handicapped, Day Activities program for Family Care Audits, swimming program and trained babysitters that will sit for families called TABS. (Trained Aides as Babysitters). (See feature on this page).

Ten years ago Wayne consisted of 2 staff, 6 clients, and 1 classroom. Today, they have 55 staff, 286 clients, and 5 facilities. . . and many creative programs.

Digest founder

aids Westchester



John Allen, assistant managing editor of Reader's Digest, presents check on behalf of Lila Acheson Wallace, co-founder of Reader's Digest, to Herbert Katzenberg, chairman of WAR'S fund raising committee.

A pre-school program for mentally retarded children, in jeopardy due to lack of funds, is now solvent again thanks to the generosity of Mrs. Lila Acheson Wallace, co-founder of Reader's Digest in Pleasantville. Mrs. Wallace's offer to match up to \$25,000 to help fund the Westchester Association for Retarded Children's pre-school programs set off a series of fund-raising ventures by WARC members and friends. They achieved their goal of raising matching funds. John Allen, assistant managing editor of Reader's Digest, presented Mrs. Wallace's check to Herbert Katzenberg, WARC vice chairman and chairman of its fund-raising committee. WARC's pre-school programs are countywide, with classrooms in White Plains, Yonkers and Katonah. On behalf of the agency, Mrs. Katzenberg expressed his appreciation of Mrs. Wallace's contribution.



Baby Sitting

Wayne "TABS" volunteers

The Wayne County Mothers' Club sponsored a Trained Aides As Babysitters (TABS) seminar during the month of March at the Wayne County ARC Day Training Center, E. Union Street, Newark, N.Y. "TABS" is a program designed to train individuals to be competent sitters for the handicapped child and provides a curriculum tailored to the needs of the child and the parent. The program provides those completing it with the necessary knowledge and experience to care for the child during the parent's absence.

Students receive an orientation on the basic handicapping conditions and behavior aspects related to them. The course also includes a multi-media first aid course, feeding and dressing, braces and wheelchairs, basic sign language, bedtime routines and how to relate to and play with the child. The seminar ran for a two-week period. A graduation ceremony and party is planned for April 2.

Volunteer instructors for the course were Karen Steitler, Maize Lohrmann, Mae Vandeveld and Doris Cole from the ARC Day Training Center staff. Also participating were Sue Hayes from the Newark Developmental Center, Frank Crudele — Williamson Volunteer Ambulance, and Mary Sprague — Wolcott Volunteer Ambulance. These instructors put together an exceptional program that gave the students not only a broader understanding of handicapped children, but

the skills they require to care for them in the home.

The entire program was coordinated by Sandi DeForge, Mothers' Club member. It is the culmination of a year's research and work. It is hoped that it may become an annual event to maintain services for the parents. Parents of handicapped children have a special interest in having competent sitters because of the special needs of their child. It is hoped this program will meet that need.

This is the first time a project such as this has been attempted in the area and the Mothers' Club has worked hard to assure its success.

"There are many services for our handicapped children. Now there is a service for the parents of those children!"

In this first class were students from all over Wayne County from the age of 14-49. These marvelous people donated their free time to take part in this course out of their concern for our handicapped children. Those completing the course will be listed in a pamphlet that will be distributed to all known parents of the handicapped, doctor's offices, schools and agencies serving the handicapped. Finally, our parents will have a list of trained sitters they may reach when they require their services.

The program outline is available for the asking to any agency wishing to undertake it. To obtain an outline, contact Sandi DeForge, 532 Ridge Road E., Williamson, N.Y. 14589.

Sullivan early intervention

Sullivan County Chapter in South Fallsburg, N.Y. is responding to the needs of developmentally delayed infants and their families through its Early Intervention Program.

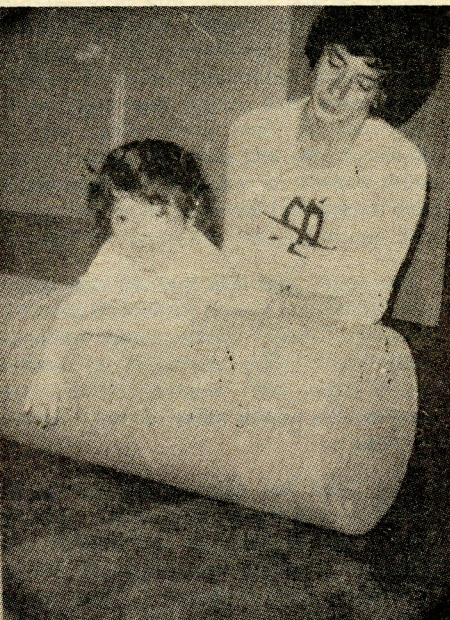
The program provides group and individual training for the child, parent counseling, home intervention and referral to appropriate advance placement.

A professional staff provides infant training in many areas of development: physical, perceptual, cognitive, communication, emotional, social and self-

help skills. Parent education, counseling, support and guidance in family development are part of the overall program designed to encourage maximum growth and development of the infant and family in their own environment.

The program is available to any Sullivan County resident, from birth to 3½ years of age, who is suspected of, or identified as, having a developmental delay or handicap (not limited to mental retardation). Referrals are made by parents, doctors or other social service agents or agencies.

For more information call or write to: Sullivan County Association for Retarded Children, Box 812, South Fallsburg, N.Y. 12779, (914) 434-3415.



Jenny Silverman, program therapist, works on physical movement with Edwin Lewis, 1½ years old.

Crosby aids

NYC AHRC

Bing Crosby made his first New York stage appearance in 45 years and selected New York City AHRC to receive half of the net proceeds of a series of 12 concerts he presented on Broadway.

The famous singer wrote to James P. Murphy, AHRC president, saying he had read of the activities of the AHRC in a New York newspaper and wanted to help the organization.

Crosby, his wife, Kathryn, and their children appeared at the Uris Theatre in Manhattan. Also appearing with them were the Joe Bushkin Quartet and Billy Byers Orchestra.

In addition to the funds received from the concerts, AHRC also received national publicity as Crosby and his wife were interviewed on leading television and radio programs.

Weingold writes on issues

No reply has been received to a letter from Joseph T. Weingold, Executive Director of the New York State Association for Retarded Children to Mrs. Rosalyn Carter, wife of the President.

The letter was written in response to the Mental Health, Mental Retardation report of Morris Associates. The issue is very clearly stated in this letter:

Dear Mrs. Carter:

We have recently read with a great deal of interest that your plan for the creation of a President's Commission on Mental Health has progressed into the budget stage, and even to a search for an executive director. We think this is a very fine move, indeed, except we are turned off completely when we read in the Mental Health, Mental Retardation Report of Morris Associates, that Dr. Peter Bourne of the Transition Team recommends that the primary focus of the Commission be on mental health, including specifically, mental retardation. We think this is a regressive step taking us back more than 20 years, into the area when we talked in the law of the "insane, idiots and imbeciles" all lumped together as if their problems, and solutions to solve them, were one and the same.

This is, again, a demonstration of the clear dominance by psychiatry of mental retardation, which is subsumed by them under mental health.

We suggest, on behalf of the 6 million mentally retarded and their families in this country, that, once and for all, we do what Presidents Eisenhower and Kennedy spoke about — treat mental retardation as a separate and distinct problem, which deserves solutions relevant to the mentally retarded. Mental illness is a question of treatment; mental retardation is a question of training, habilitation and rehabilitation.

It seems to us, that those who have either not read, or have chosen to ignore the demonstrations and literature of the past 15 years, can once again lead this Nation into this confusion of mental illness and mental retardation.

We urge you to reconsider your position and establish, if you will, a National Commission on Mental Retardation, as well as one on Mental Health.

Certainly the mentally retarded may be subject to emotional disturbance, and even mental illness, but they are also subject to cancer, kidney failure, and all the other human ailments the afflict humanity.

Let us, once and for all, understand that what we must do for the mentally retarded is education and treatment in nature, and psychiatry, although it may have some place in this picture, is by no means anywhere near the dominant factor. The mental health clinics of this country do not deal with the mentally retarded and, in fact, their intake policy, for the most part, prohibits this. What then are we doing, but succumbing to old ideas and old cliches.

I am sorry so early in your husband's administration, to raise an issue such as this which may well polarize the persons dealing with these problems.

But, once and for all, for God's sake, let us do justice to the mentally retarded. Let us give them their rights, not hand-outs under the guise of mental health.

This letter to the editor of the New York Times was written recently by Joseph T. Weingold in response to an editorial in the newspaper:

To the Editor:

May we congratulate the Times for its front-page article on Nov. 26 regarding the plight of babies and young children who should not be in the city hospitals.

The sad fact of the matter, not expressly stated in the article, is that one of the major departments dealing with residential services for handicapped children, the Department of Mental

Hygiene, has renounced its responsibility with regard to such children. Its non-expressed policy is not to accept mentally retarded babies. By some impossible stretch of logic, this is attached to the policy of "deinstitutionalization". If the Department of Mental Hygiene would assume its rightful responsibility with regard to mentally retarded children now in the city hospitals, most of them would not be where they cannot get developmental services.

This is but another indication of the paralysis of the huge bureaucracy of the Department of Mental Hygiene, chained to a system of decision-making where the buck stops nowhere. Each director of a Developmental Center can decide for himself whom he will accept and whom he will not. Certainly it is more difficult to deal with severely mentally retarded babies and young children, but what hope is there for them if the one state agency set up for that purpose does not carry out its responsibility?

In an article in The Staten Island Advance earlier this year, Joseph Weingold was misquoted as "applauding" the governor and saying his agency had been seeking the split for 12 years.

In order to correct the wrong impression created by the quotation in the article, Weingold wrote a letter to the Staten Island Advance. This letter states the views of the N.Y.S. Assn. for Retarded Children regarding the issue:

To the Editor:

I should like to correct a statement attributed to me by Mr. Robert Miraldi in his article which appeared in the Thursday, January 6, 1977 issue of the Staten Island Advance, in which he talks about Governor Carey's proposal to split the Department of Mental Hygiene into separate Bureaus for Mental Health; Mental Retardation; and Alcoholism and Drug Abuse. The statement is "The Director of the New York State Association for Retarded Children 'applauded' the Governor and said his agency has been seeking the split for 12 years."

What I said was the New York State Association for Retarded Children applauded the Governor's intent to separate mental retardation from mental illness and drug abuse (now listed by the Governor as "substance abuse"), but I disagreed strongly with leaving this separate entity in the Mental Hygiene Law. I further stated Senator Conklin and Assemblyman Steingut in 1975 introduced a bill to create an Office of Developmental Disabilities and Mental Retardation in the Executive Department that passed overwhelmingly both houses, but was vetoed by the Governor. We are glad the Governor has come around to realizing the mistake of such a veto, but we could in no way agree with the method of implementing this split.

You might add, too, that we look with a very jaundiced eye on those who object to making "clear distinctions between disabilities". The confusion of mental retardation with mental illness has resulted in a horror story for the mentally retarded.

The time has come when the 600,000 mentally retarded and their families should be treated as a distinct and separate problem from mental illness, alcoholism, and drug abuse. It is our intention to support as strongly as we can the 1975 Conklin - Steingut bill.

It is interesting to note that all requests of the Governor's office to tell us what was wrong with the bill or suggest changes have gone unanswered.

Rockland places retarded in jobs Maroon is placement director

Because of concern about employment for the mentally and physically handicapped, the Rockland County legislature created the Office of Special Placement within the County Personnel Department. Jim Maroon, a former member of the State Association Board of Governors, was named special placement assistant in the new office.

The main responsibility of the Special Placement unit is to find jobs for the mentally retarded and physically handicapped in both private and public employment. Without help, such persons find it impossible or extremely difficult to obtain remunerative employment to make them productive, tax-paying citizens. Mentally retarded persons, and the physically handicapped as well, are like most other people in appearance and in their desire for employment, friends, and family independence.

Comments in a letter from Maroon to the State Association note some important facts about the work habits of the mentally retarded as well as suggestions to employers.

The mentally retarded can do a job well if it is within their range of competence and if they feel comfortable and happy doing it. As a rule, the retarded employee performs best in simple, repetitive or short cycle jobs like manual labor, cleaning, washing dishes, bench assembly work, clerical, running errands or tasks involving hand operations. Because a retarded person has a more narrow field of understanding, he or she is less likely to see the relationship of one thing to another. When such a person has learned a routine, it is done well with a remarkable persistence. Most often they are found to be loyal and dependable with good work habits.

STUDIES SHOW POSITIVE RESULTS OF MR. WORK HABITS

Valid well established studies and surveys made among employees of the mentally retarded show that:

1. Insurance: No increases in compensation costs nor lost time injuries.
2. Physical adjustments: Most handicapped workers require no special work arrangement.
3. Safety: 96 per cent rated average or better on and off the job; more than half were above average.
4. Special Privileges: They want to be treated as regular employees.
5. Job Performance: 91 per cent rated average — or better.
6. Attendance: 79 per cent rated average or better.

HELPFUL TIPS FOR EMPLOYERS

Only a few suggestions are recommended to employers in order to get the best possible service from a mentally retarded worker. These suggestions are reasonable and no different from what one would do for any new non-handicapped worker. Talk to him or her on a person to person level as you would talk to anyone else. Try to be more specific as if speaking to someone in the upper levels of grade school. Speak in concrete terms. If for example you want him to put something away, show him exactly where "away" is. Demonstrate what you want him to do; don't just tell him. Show him where things are — lockers, rest rooms, supply room — in the same way as you would for any new employee. Take your time and make sure he understands. Take extra care to explain about working hours, proper clothes on the job, his work station, whom he reports to, what his pay will be. Ask an occasional question to make sure he is keeping up with you. Introduce him to fellow employees and supervisors. He may seem a

bit withdrawn at first, but he will warm up once he gets to know the people. Present him as a regular staff member without alluding to any handicap, assuming that he is just the same as everyone else. Be sure to lend him a helping hand when new situations and new problems arise which he needs help in coping with. And finally, make a note of his on-the-job strong points, among which the following are predominant:

1. He wants to make good. He will work particularly hard to make good.
2. He wants to stay put on the job with no desire to "job hop". He is happy to learn the job and remain with it.
3. His attendance record is generally better than average.
4. He will be a willing worker and will stay at routine tasks.

When he proves himself to be a good worker, pass the word on to other employers that "it can be good business to hire qualified mentally retarded workers."

Referrals are received from all the County and State agencies serving the mentally and physically handicapped in Rockland County.

Childhood disability for SSI

Responding to a new Congressional mandate, the Social Security Administration has issued proposed criteria for making SSI disability determinations among children under the age of 18. The amendments to existing SSI regulations are intended to implement Section 501 (b) of P.L. 94-566 which directs SSA to issue childhood disability criteria by February 17, 1977.

The basic requirements for determining childhood disability in existing regulations are unchanged. Under these regulations, a child under age 18 is considered to be disabled if: (a) he is unable to engage in substantial gainful activity; (b) his impairment(s) meets the durational requirements; and (c) his disabling condition is either a listed impairment or the medical equivalent.

Upon until now, a single regulatory list of impairments has applied to both children and adults. This section is retained in the proposed regulations. However, a new subdivision is added to deal with the evaluation of disabling conditions peculiar to childhood.

The criteria for determining the eligibility of mentally retarded children is found in Section 112.00 of Part B of Appendix 1. Perhaps, the most noteworthy features of this new criteria are:

— children with an IQ of 50 or below would be considered disabled for SSI purposes regardless of whether other associated handicapping conditions exist or not;

— children with an IQ of between 60-69 would either have to: (a) have a physical or another mental impairment which restricts their functional or developmental progress; or (b) have chromosomally proven Down's syndrome in order to be found disabled;

— youngsters whose age and-or condition preclude formal intelligence testing, could be found disabled if they failed to achieve those developmental milestones generally acquired by children no more than one-half of their chronological age.

Budget threatens long term work

Under a law this Association sponsored some years ago, the Education Law was amended to provide for state support to the agencies providing long-term employment of the mentally retarded incapable of self-sustaining employment. The rate set in the law was up to \$1500 a year. Because of veto by the Division of the Budget, the initial support was \$1200 a year. This law was later amended to include mentally ill and then physically handicapped. The budget, however, was not raised to take care of these additional people. Thus, the amount of funding was reduced to \$1000 a year.

Under the budget, as proposed by the Governor and adopted, only \$4½ million, the same as last year, is appropriated. This means there will be at least a \$700,000 shortage to meet the \$1000 a year, with a possible cut to \$875 a year. This may well mean the death of this program in many agencies.

The agencies concerned with this are now united to push for a supplemental budget of at least \$2 million to bring the reimbursement rate at least up to \$1200.

It has been estimated it costs the agencies at least \$4000 a year for each long-term employee in sheltered workshops for which the state now reimburses only \$1000.

On parent relief from private fees

At the request of the New York State Association for Retarded Children, Assemblyman Gordon W. Burrows of Westchester has introduced legislation to raise the reimbursement rate Social Services pays to private institutions for mentally retarded adults from the present \$650 to \$900 per month. Additionally, the bill (A. 3924) wipes out the differential between reimbursement for institutions downstate and upstate.

This bill is necessary because of the demand by private institutions on the parents for reimbursement of \$100 to \$200 a month more than the state pays them. This has resulted in deep anxiety to the parents and the possibility that many of these adults may have to return to institutions if put out by the private schools.

The Department of Mental Hygiene also has expressed concern and has developed a plan by which the Department itself would reimburse the private schools for the additional fees. This, however, was vetoed by the Division of the Budget and the situation remains critical.

NLRB rules in Albany

In an action brought before the National Labor Relations Board by local 200, General Service Employees' Union against the Albany County Chapter of the State Association, the National Labor Relations Board ruled it had no jurisdiction over the case and would not order an election.

Reviewing the services rendered by Albany County Chapter, the Board found that, with respect to the school, the employer was providing a state mandated service through its contracts with local school districts. With respect to the sheltered workshop, the employer was providing a number of services authorized, encouraged, and funded by the Federal government, the State of New York and the County of Albany. Finally, in order to obtain these contracts in funding, the employer must meet certain standards concerning its facilities and personnel.



Erie turns blizzard to advantage

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What happened to the Erie County Chapter, New York State Association for Retarded Children, during the memorable blizzard of 1977? All facilities were shut down for several days, many windows were broken in the greenhouse by the severe weather conditions and employees of the workshop lost several days' wages.

However, they turned a devastating situation into a profitable endeavor. Allentown Industries, the adult sheltered workshop of Erie County ARC, is selling "Buffalo Snow!" "Buffalo Snow" is actually liquefied snow from the Blizzard of '77 stored in a small glass vial which is attached to an attractive plastic stand. A descriptive booklet called "Chill Factors" accompanies this memento and lists some remarkable statistics about the blizzard and what happened to Western New York residents.

Employees of Allentown Industries printed the labels and booklets, and assembled packaged and mailed out the orders for this unique souvenir.

Prenatal diagnosis project funded

Prenatal diagnosis of Down's Syndrome, and other fetal disorders, by amniocentesis has received approval by the New York State Department of Health. The program will be operated by the Medical and Health Research Association in the New York City Health Department's Laboratory at 26th Street at 1st Avenue. It is expected to serve 4,000 women a year, aged 35 or older or in other specified high risk categories.

During the time renovations to the building are completed, New York University Medical Center, sponsor of the project, hopes to purchase necessary equipment, employ staff and launch a program of public and professional education. The laboratory could start accepting specimens by this summer.

Rene I. Jahiel, M.D., Ph.D., Research Professor at New York University Medical Center, expressed personal thanks to Joseph Weingold for his enthusiastic encouragement and help when the program was being designed and the proposal was being submitted. Another project of interest to Professor Jahiel is the education of severely and profoundly retarded children.

ARC joins protest

Disabled in Action

In a telegram sent to the Disabled in Action LTD, of which the New York State Association for Retarded Children is a component part, the Association supported the stand that organizations speaking for the handicapped are not adequately represented.

The telegram reads: The New York State Association for Retarded Children, speaking for 58 chapters and 35,000 family memberships, endorse completely your position for testing Governor Carey's choice of delegates to the White House Conference on handicapped individuals. Not a single representative of any consumer organization for the mentally retarded, including this Association, is on the list. We join with you in your protest.

Of the 32 member delegations to the White House Conference, only 4 are representatives of any consumer group of the disabled, and not a single one is a representative of the Association for Retarded Children, the largest single deliverer of services for retarded in New York State.

The Steering Committee for so-called State Regional Conferences on the Handicapped voted not to hold elections for the New York State delegation at the Regional Conferences. Instead, 16 members of the 19 member Steering Committee were nominated and appointed to the delegation, hardly a democratic process.

This action of the Governor seems to fall into line with actions regarding to White House Conferences since 1950 when, time and time again, the mentally retarded and their representatives have been systematically ignored.

Court accepts M.R.

girl's testimony

The state's highest court has ruled that a mentally retarded girl's confused testimony was clear enough to convict a Long Island man of statutory rape. The court said that to disallow testimony from the "mentally infirm" would be to deny them their right to a hearing.

The Court of Appeals ruled recently that the trial judge was correct in admitting the girl's testimony in the 1974 case. The man's lawyer had argued that the girl did not understand courtroom proceedings.

The Court of Appeals ruled recently that the trial judge was correct in admitting the girl's testimony in the 1974 case. The man's lawyer had argued that the girl did not understand courtroom proceedings.

The defendant was a bus driver who took the 17 year old girl to special classes for the retarded, according to his lawyer. On the stand, the girl said that the defendant had sexual relations with her twice. Later she said she didn't know what this meant. The judge's opinion states that the defendant told the Grand Jury that he had sexual relations twice with the girl only after "her advances eventually weakened his moral inhibitions". The incident was discovered when the girl checked into a hospital with heavy bleeding from an incomplete abortion.

"An overly restrictive approach to the evidentiary rules respecting testimonial capacity could work to deny the mentally infirm the right to complain of their treatment at the hands of those normally responsible for their care", Jason wrote in his opinion. "While we recognize the need to guard against the occasional abuse . . . we also refuse to ignore the practicalities imposed by an even harsher reality".

YOUTH Group News

For and About our YOUTH
ARC Chapters around the state

WEST SENECA YOUTH ARC

The first meeting of the newly organized YOUTH ARC group was held on Tuesday evening, March 29, 1977 at Ketchum Hall at the State College Campus in Buffalo. An eager group of young people met to organize and initiate a YOUTH ARC Chapter of the West Seneca Developmental Center ARC Chapter.

Shirley J. Reynolds, a member of the Board of West Seneca Chapter, organizer and advisor for this group, opened the meeting with a general overview of the State ARC organization and the role of the YOUTH Chapters. The newly formed group, with Kim M. Gilpatrick as chairman, has already staffed several important committees. Membership: Lyn Shroeder, Cindy Halen, Patti Palys, John Naddinski; Fund Raising: Frank Bolt; Publicity: Tom Reynolds and Brian Szpakowski. Kathy Baker, president of State YOUTH ARC Board, will be the guest speaker at their next general meeting, and will provide an overview of YOUTH ARC in our state, indicating the wide range of services and programs provided by concerned youth across New York State.

If you're interested in receiving additional information, or in becoming a member of the West Seneca YOUTH ARC, please contact Shirley Reynolds as follows: Business No. — 833-3231, Residence No. — 876-0577.

WELCOME SHIRLEY

Long Island's newest junior auxiliary will be called Shirley and the Mastics Junior Auxiliary. At the first meeting, held Tuesday, February 21st, April Gomez was elected president and September Fitzgerald, a vocational training instructor at the Bohemia workshop, was appointed adult advisor.

If you want to get on the mailing list of this new and energetic group, please contact April at () 399-0015.

HUDSON FALLS YOUTH ARC ORGANIZED

Students at the Hudson Falls Senior High School have recently organized a local unit of the YOUTH-ARC.

The group plans to provide activities for retarded children by raising funds to purchase a movie projector; supervising and teaching bowling; conducting movie trips; teaching dancing; taking them roller and ice skating.

The ARC plans to offer its services to the parent organization to train its own members in social work and to seek employment in area businesses for the retarded. President of the Hudson Falls YOUTH-ARC is Karen Rock; Vice-President is Beth Stanton; Secretary, Kathleen McNaughton; and Treasurer, Amy Clark.

Faculty advisors are George Stasko and Norma Scivetti. Other members include Fran Colvin, Laura Cornell, Debbie Hitchman, Bette Jones, Nance McGuire, Peggy Simpson, Diana Valentine, Robin Waite and Pam Young.

SMITHTOWN

The Smithtown Junior and Senior Auxiliaries recently cosponsored a successful Square Dance which was a huge success.

Special thanks to the juniors for their pledge of support and to Mrs. Cathy Matthews who chaired the dance for the seniors. It was encouraging to see the cooperation and enthusiasm exhibited by those who helped make the dance the success it was. Now that they have their feet wet they're looking forward to their next big event.

Finally making it

Years back, when a group of "young" people met in New York City, they weren't just thinking of fun. They were serious about forming an organization — an organization that would serve as a friend to persons who are mentally retarded, committed to help them live and work in a better world, and to serve with the NYS-ARC, Inc. in their programs and other efforts to help the mentally retarded. They were to call it New York State Youth Organized and United To Help the Association for Retarded Children. (Y.O.U.T.H. ARC). They had an unspoken dream that someday YOUTH-ARC would be established throughout the State. At the time, not many people shared their dream. Some thought it would never last. Many adult ARC Chapters across the State had no idea what YOUTH-ARC was. Most weren't even interested, but that was almost nine years ago and that's no longer true.

Get thumbs moving

Make tracks for Syracuse!

By Kathy Baker

State Y.O.U.T.H. is planning a fund raiser on the state level. It will be a week-long event at the State Fair in Syracuse at the end of August.

We will have a booth where we will sell tickets for a raffle and distribute information on YOUTH. A special attraction will be our "Balloon Race" and here is how it works:

The purchase of each balloon (\$1) automatically entitles you to a chance to win \$100. During the Fair, YOUTH-ARC members will be on duty taking your orders for balloons, and attaching a pre-addressed card, bearing your name.

Today that dream of a "few" is exploding into reality. In nine years, we have moved from a few interested people to 50 established YOUTH groups with individual membership exceeding 2000. You can approach an ARC Chapter today and they can tell you what YOUTH-ARC really stands for — it isn't the American Red Cross!

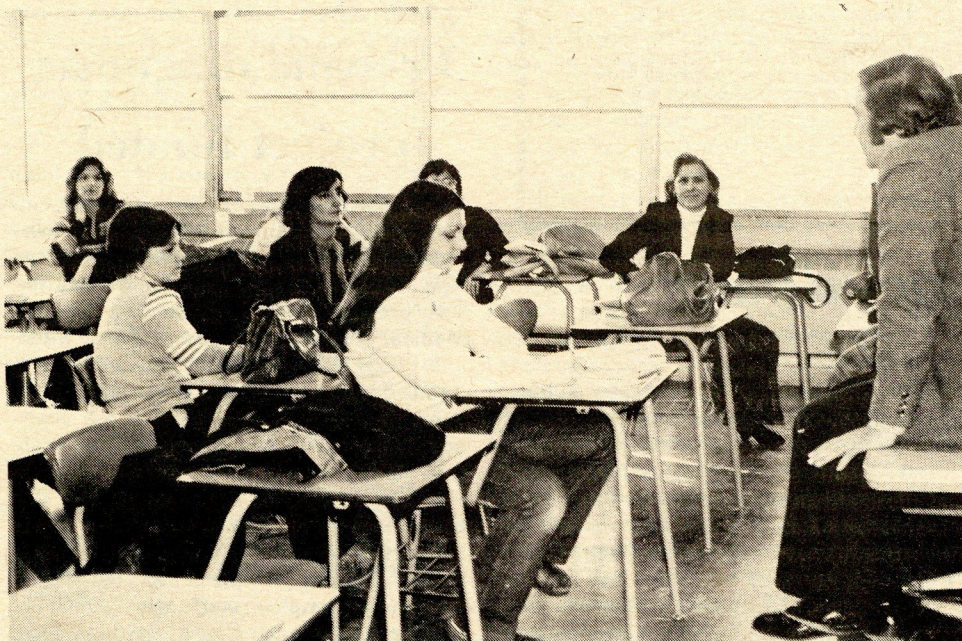
We have incorporated our dream of a strong, state-wide legion of youth into our motto: **Hand-In-Hand, Together We Can.** Our dream is becoming a reality because of you. We did it **together**. Nobody gave up when things looked bad. That's why we welcome new youth members from Oswego, West Seneca, Tompkins, Broome, Tioga, Orleans, Saratoga, Syracuse, Geneseo, Albany, Hudson Falls, and Shirley.

The next ten years can be easier if we do it together. Join the YOUTH movement now. **Together We Can.**

Balloons will be launched at intervals each day of the fair. The balloon found the farthest from the fair site, within a 30-day period, will gain its owner the award.

This effort to raise money for YOUTH-ARC will require a lot of coordination throughout the state. So, if you have time, please give us a hand. Also, we are in need of raffle prizes and certainly would appreciate your help in this area. If there are any ARC members in the Syracuse area who could put up a few people during the fair, please get in touch with us. We've gotten this far **Together**, let's make it big in Syracuse.

New Youth Chapter in Albany



Members of Yonkers YOUTH-ARC

A group of young people who wish to work for and with mentally retarded people has recently formed at Lincoln High School in Yonkers, N.Y. in conjunction with the Westchester Chapter of NYARC. Advisors to this group of young people are Ms. Leni Goldstein and Ms. Bobbie Cohlín, both special education teachers in the Yonkers School system.

The group has been meeting with parents of retarded children and touring

the facilities maintained by the Westchester Chapter in order to attain a greater understanding of mental retardation. The Chapter is also making plans for recreation activities for clients of WARC and other retarded citizens of Yonkers. The local special Olympics have also recruited them for assistance.

So far the new Chapter has had an active start and is heading for even greater future achievement.

NORTH FORK

All was quiet on the North Fork front this winter. So we looked forward to our quarterly meeting in the spring when the film "Access" was shown. This is the documentary about a mentally retarded boy. Afterwards, we had an opportunity to meet with, and speak informally to, Cynthia Derr, Community Affairs Specialist for the Suffolk Chapter.

The date for our first and most important benefit of the year has been set for Thursday, May 5th. This is our annual roast beef dinner sponsored by the Southold American Legion.

Plans are being made for an intensive membership drive. It will probably coincide with the move of the Riverhead Workshop into the Commissary Building at the Suffolk County Airport in Westhampton Beach.

VOLUNTEERS NEEDED FOR SUFFOLK YOUTH

Dear Readers:

Our youth auxiliaries have proven they are an outstanding group of young people dedicated to working with, socializing with, and fund-raising for, their mentally retarded friends.

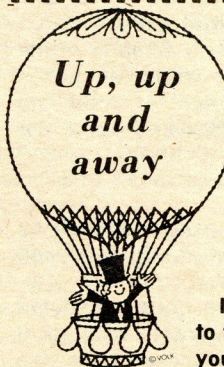
They enjoy taking field trips to the animal farm, baseball games, plays and sometimes just a shopping trip. Picnics, camping and recreation programs are another source of enjoyment for both teen and special friend. One auxiliary started a bread baking program and, believe me when I say it, this group held everyone's attention for five hours straight and the end result was delicious!

Another group has taken young adults into the city to see a Broadway play. Many children and young adults are able to participate in Suffolk Olympics as a result of training programs set up by junior auxiliaries. However — the auxiliaries can function much more effectively if they have a mailing list available to them to send invitations out.

If you would like your son or daughter to be on a junior auxiliary mailing list please fill out the coupon below and mail it into the Chapter office. All information will be kept strictly confidential.

Jackie Mott
Suffolk County
Y.O.U.T.H. Advisor

Name _____
Address _____
Phone No. _____
Particular Hobbies _____
Special Programs You Would Like _____



Advance Notice

If you can't make it to the fair this year and you would like to have a

chance to win, you can get your balloons now. You can send your name, address, phone number and \$1.00 per balloon to: Kathy Baker, 159 Belcoda Dr., Rochester, N.Y. 14617.

The day of the fair a balloon will be released in your name. Sound easy. You bet it is. So why not send up 2 or 3 or 5 balloons.

Education challenge rejected

EDUCATION CHALLENGE REJECTED

Late last year, the United States Supreme Court rejected a challenge by parents of handicapped children to a New York Family Court Act which provides full state support for the education of blind and deaf children, but only partial support for other handicapped children.

The appellants are parents of three handicapped children, not deaf or blind, who are in need of special residential educational training.

SUPREME COURT HEARING DENIED

The Supreme Court denied the parents' request for a hearing and, in so doing, let stand the ruling of the State of New York Court of Appeals which held that the section of the Family Court Act in question is constitutional.

In the suit, the parents alleged that the New York statute denied them equal protection of the law in two ways:

1) Requiring them to contribute to the maintenance costs (room and board) of their children's education, when no such contribution is required of parents of deaf or blind children, is discriminatory; and 2) although the statute authorizes such payments by parents of handicapped children in New York City, the same is not true for children who reside outside the city.

JUDGE USES "RATIONAL BASIS" TEST

In the opinion of February 17, 1976, written by Judge J. Jones, the court notes that, at the threshold of consideration of any equal protection claim, is the determination of the applicable standard of review. In this case, Jones points out, the appropriate standard is the traditional rational basis test, and states that a rational basis does exist for the distinction made in relieving parents of blind and deaf children from any financial responsibility in connection with their children's education, while at the same time requiring parents whose children are otherwise handicapped to contribute to the maintenance component of educational expenses.

There can be no doubt that, as a matter of history and tradition, our society has accorded special recognition to the blind and to the deaf in the field of education as elsewhere. . . In the related field of social services, assistance to the blind has long been recognized as a special category. . . The Federal Government has also long accorded privileges and benefits to the blind which are not available to other handicapped persons. . . We think that the Legislature acts rationally when, in the exercise of its authority and responsibility to identify concerns of the State and to make provision with respect thereto, it takes into account distinctions which carry

the imprimature of historical authenticity . . . the policy judgments and the priority determinations of our history are not totally to be rejected, especially when those judgments and determinations have enjoyed public acceptance for a long period of time. . .

Judge Jones also added in the appeals court decision, "Our Legislature, in granting the preferences to parents of the blind and deaf, may well have judged, at the time, that children with these handicaps were more educable in general than were those with other handicaps."

In commenting on the appellants' equal protection arguments with regard to residence in and outside of New York City, Judge Jones noted that this argument is predicated on a false premise and that there is no difference in the authority of the courts within and without the city. However, he does point out that the section of the statute which is applicable outside the city contains no comparable provision to the section of the statutes in question. According to Jones, this has been described as a legislative oversight in the 1964 amendment.

Appeal Dismissed by U.S. Supreme Court, No. 75-1670 45LW 3225, Oct. 5, 1976.

Chautauqua receives

\$50,000 grant

The Chautauqua County Chapter of the State Association for Retarded Children has received a \$50,000 grant from the Statler Foundation.

Michael J. Raymond, Chautauqua executive director, said the grant will allow training programs in food preparation to be initiated for clients of the Jamestown Achievement Center. Other program swill include dishwashing, menu preparation and the operation, maintenance and cleaning of restaurant equipment. Such training will prepare clients to take jobs in area restaurants and kitchens.

He added the grant includes the purchasing of necessary equipment and will pay the salaries of the professional cook and home economist to be hired.

The clients will be able to prepare food for a menu, offering a variety of dishes on a daily basis, to the facility in Jamestown. The cafeteria will have a potential of serving 200 meals at one time.

"If this program at our Jamestown facility proves to be successful, it may pave the way for establishing similar programs at other centers in Chautauqua County," Raymond noted.

Education definition of M.R.

Mentally retarded and seriously emotionally disturbed children are included in the definition of handicapped children eligible for the services and protection authorized by the Education of All Handicapped Children Act (PL 94-142), implemented by a proposed rule making in the 95th Congress. The regulations, published last year by the Bureau of Education of the Handicapped in the Federal Register, govern the Act's Part B program of formula grants to state and local educational agencies for assistance in educating the handicapped. Incentive grants to develop programs for handicapped children in the three to five year age range were also covered.

The rulemaking defines both mentally retarded children and seriously emotionally disturbed children. A mentally retarded child is one who possesses a "significantly subaverage general intellectual functioning" that exists "concurrently with deficits in adaptive behavior" and is manifested during the child's developmental period, adversely affecting his educational performance.

On the other hand, a "seriously emotionally disturbed" child is defined as having, over a long period of time and to a "marked degree", a condition characterized by:

- an inability to learn which cannot be explained by intellectual, sensory or health factors (but not considered a specific learning disability, which the regulations define separately);

- an inability to build or maintain satisfactory interpersonal relationships with peers and teachers;

- inappropriate types of behavior or feelings under normal circumstances;

- a general pervasive mood of unhappiness or depression;

- a tendency to develop physical symptoms or fears associated with personal or school problems.

The term includes children who are schizophrenic or autistic. Children who are socially maladjusted, but not emotionally disturbed, are excluded from the definition of handicapped.

Parental liability

end probable

The perennial bill to remove parental liability for fees to the Department of Mental Hygiene for services rendered in mental hygiene facilities to their children has a strong possibility of passage this year.

According to information from the administration, removal of such parental liability may result in a \$7 million windfall to the state. Under the present SSI law, the assets of the parents of minors are considered as part of the assets of the minors in determining financial eligibility for SSI. If such parental liability were removed by law, there is a strong possibility all these minors would be eligible for SSI with the resultant income of SSI and Medicaid to the state.

This bill was passed four times during the Rockefeller administration and vetoed four times by Governor Rockefeller.

The present information is that the total income by all direct parent payment is about \$600,000. We have been unable to discover from the Department of Mental Hygiene what it costs to collect this \$600,000.

Shameful budget cut

"Tender mercies of local legislatures"

The six county representatives who defeated the Association for Retarded Children's compromise budget request should be ashamed of themselves. The cut, made in the name of economy, will save county taxpayers a total of \$700, or about three-tenths of a penny per taxpayer for the year. For that savings, the county will lose about \$20,000 in services — counting state reimbursement and income from the association's sheltered workshop. More importantly, what will be lost through the program's cut in terms of human potential is incalculable. Can't we afford to give retarded children the chance to be children? The alternative is that they be prisoners of a treatable handicap and literally, prisoners in degrading — and costly — state institutions.

The most charitable thing that can be said about the six representatives — Murray Ames, Domenick DiScala, Warren Kinney, Richard Schlee, Andrew Tisenchek and Donald Trinkino is that

they were trying to fool the taxpayers. By making the cut, the six achieved the appearance of having lowered the budget by \$19,339. The picture is misleading because it does not include the income side of the budget. There is a good possibility that because of the program's income, the county's share of the \$19,339 would not have been close to the maximum of \$700.

The other possible reason for the cut is that the six representatives were reflecting a mean-spirited philosophy: that people, no matter what the need, no matter what the situation, no matter how little the cost, no matter how great the benefit, do not deserve to be helped.

We would suggest that constituents of these representatives contact them to ask which of the possibilities is correct. And, we should ask ourselves: how great a price, in terms of our own humanity, are we willing to pay for a three-tenths of a penny savings?

From Cooperstown, N.Y., Freeman's Journal

How education committee works

GEORGIA SULLIVAN PROTESTS LACK OF BUS AIDE

We can all take a lesson from Georgia R. Sullivan, Chairperson of the Mid-Hudson Region New York State ARC Education Committee.

Georgia wrote this letter to Dr. Adler, the Supervising Principal of the Cornwall Central School District in Cornwall, New York:

Dear Dr. Adler:

As Mid-Hudson Region Chairperson for the NYSARC Education Committee, I am writing to express my concern about the lack of safety for the severely handicapped school-age children who are being transported from Cornwall to the AHRC

classes at Gidney Avenue Memorial School in Newburgh.

Although a bus-aide is not mandated by law, it is still the responsibility of the Cornwall Central School District to insure that the ride to and from school be safe. The children concerned are severely retarded and are not ambulatory. As we are both aware, the bus driver is not supposed to leave his seat so that if an accident did occur, there would be no one to assist these children.

The cost of a bus-aide can be included in the busing contract, and 90 per cent of this cost will be reimbursed the following year. I do not believe that the Cornwall Central School District would not want to insure the safety of these children, and

hope that a bus-aide will be added to this bus as quickly as possible.

At this time, I would also like to notify you that these children should, because of the severity and multiplicity of their handicaps, be placed on a lift bus as soon as possible.

If you have any questions about the bus-aide, may I suggest that you contact: Mr. Salvator Tavormina, Associate in the Education of the Handicapped, SED-Mid-Hudson Region.

Thank you for your cooperation in this matter.

Sincerely,
Georgia R. Sullivan, Chairperson
Mid-Hudson Region
NYSARC Education Committee

Home pay proposed

A bill introduced by Senator William T. Conklin, together with John Colandra and Abraham Bernstein, (S. 4267) and cosponsored in the Assembly by Assemblyman Butler and others (A. 7694), proposes legislation to reimburse families which maintain a home for retarded relatives who would otherwise be institutionalized.

The state now reimburses families who have brought home relatives who have been previously institutionalized for two years or more. This bill would extend reimbursement to families who take care of their own members, regardless of whether they have already been institutionalized or not. The bill provides for reimbursement at family care rates.

"This bill will help to stem the rising tide of degrading and expensive institutionalization of the retarded", stated Senator Bernstein. "Every family reimbursed under this bill would be taking care of a person who would otherwise be in an institution, at great financial cost to the state and the greater human cost to the dignity and humanity of the person cared for."

The decision of the Department of Mental Hygiene to reimburse families who take their children home from institutions at family care rates has polarized the state with an avalanche of protests to the State Office from families who never institutionalized their children. It is hoped that the passage of this bill will redress that inequity.

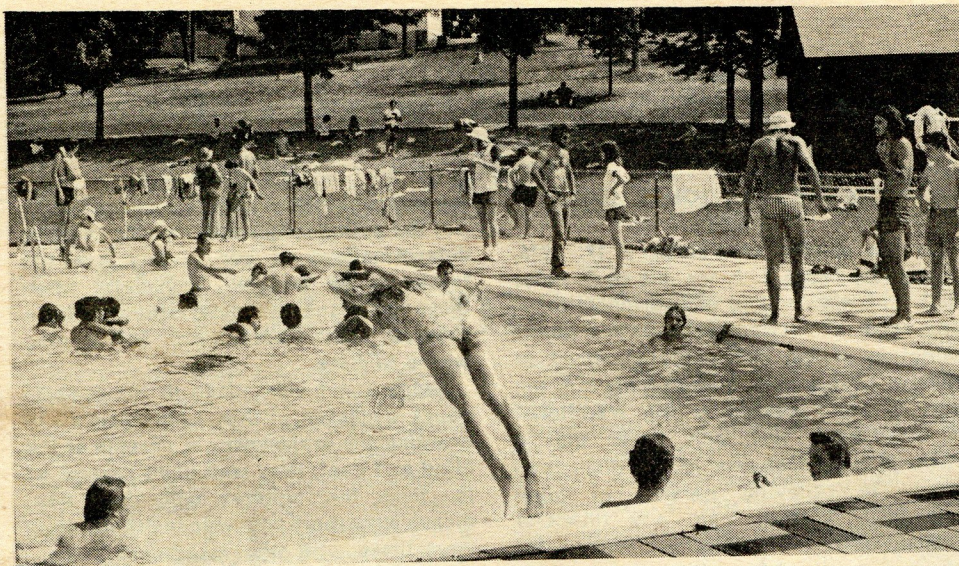
Conklin speaks moonlighting & money

"The state isn't doing enough to assure the rights of its retarded citizens and their families," Senator William Conklin told an audience recently in Rochester, New York. He said the state is "paying twice" for the services of some professionals in the Department of Mental Hygiene who moonlight at other jobs. Some of the doctors and psychiatrists put a 40 hour week into their "part time" outside jobs, he stated. "How many patients can a psychiatrist treat a week before it is either malpractice or neglect?", Conklin asked.

Conklin, who is a parent of a retarded child, was described by John Regan, executive director of the Al Sigl Center, as "The man who has written almost all of the legislation on programs and funding for the retarded in the last 20 years."

The Senator was asked to take time out from his recent election campaign to come to Rochester to address the Monroe County Chapter of the Association for Retarded Children. Conklin said the state has lately been reducing the number of patients at its institutions for the retarded, but the institutions have been allowed to continue operation on large budgets. Those budgets should be reduced and "state money should accompany the (retarded) person back into the community, "if you're going to break down big institutions into smaller community programs, the money should follow the clients".

The state should use the money it saves when it breaks down the larger institutions to encourage families of retarded children to keep the children in the community "where they belong", but often the retarded are turned back to the community where private agencies have to pick them up at the state's expense, he said.



Water programs at Camp Loyaltown-Loyaltown Lodge include swimming in this heated pool and lake boating. The staff emphasizes individual instruction.

Nassau registration open

Enrollment is now open for the 1977 season at Camp Loyaltown — Loyaltown Lodge, the Hunter Mountain sleep-away camp operated for the past four years by the Nassau County Association for the Help of Retarded Children.

While attendance is primarily from Nassau County, campers are accepted from other areas of New York State. Last year over 500 retarded children and adults attended the camp's three sessions which start on July 3. To participate in the program, a camper must be trainable and ambulatory, without restrictive diet. There is a fee of \$290 for each three week session and \$225 for the two week adult session. The camp program features a wide range of swimming and boating activities as well as active sports such as

softball, basketball and volleyball. Gymnastics, arts and crafts, music and drama are also a regular part of the activities scheduled. Social activities are also part of the camp's program.

Camp Loyaltown is located on nearly 250 acres, approximately 125 miles north of New York City. The camp features modern cabins equipped with electricity and hot water. Each cabin houses eight campers and two staff members. In addition to a large lake with a boating dock, there is a heated pool. An infirmary is on the Loyaltown campus.

Enrollment information can be obtained by writing the Nassau AHRC, 189 Wheatley Road, Brookville, N.Y. 11545 or by calling the Loyaltown office at 516-626-1000, Ext. 31.

State orders theft watch

Thefts of food, linens, office supplies and other state property — unofficially estimated at \$5 million annually — have caused the State Department of Mental Hygiene to order a tightening of security and inventory control throughout its network of 50 institutions for the mentally ill and mentally retarded.

The Department urges swift prosecution of employees or others caught with stolen property. The move reflects the beginning of more centralized control over security.

The Deputy Commissioner for Administration of the New York State Department of Mental Hygiene said the security directive authorizes the immediate hiring of private investigators and security personnel where state security units are inadequately staffed. He said CMH wants it understood that theft is a crime and a willingness to prosecute can be an effective deterrent.

A spokesman for the State Civil Service Employees Association (CSEA), the union representing approximately 65,000 DMH workers, said the theft estimates appear grossly inflated.

Directors of DMH facilities share the common complaint of not having sufficient security personnel. They agree, however, that even with tighter controls, pilferage would remain one of the most difficult crimes to control. In some cases, increased security, including electronic surveillance equipment, helps solve serious theft problems at some centers.

Reports from directors of DMH facilities include comments that thefts increased in the past year along with losses of employee and patient cash and other valuables. The items stolen are often those whose prices have skyrocketed in area markets. Dr. Herman B. Snow, director of Hudson River Psychiatric Center at Poughkeepsie believes the institutional crime rate fluctuates with the local economy and, in many instances, parallels the crime rate of surrounding towns and cities. One report includes two cars stolen from a facility's parking lot.

The DMH directive to tighten security and inventory control is now in effect.

Pendler story on travel training

There are many parents of mentally retarded children who share the same trepidation as Betty Pender, Chairperson of N.Y.S. ARC's Education Committee, did when it comes to "letting go".

The very moving personal story of how Mrs. Pender taught 20 year old Lisa to travel to her program in New York City each day, without her mother to take her, appeared in the February issue of The Exceptional Parent magazine.

The process was a learning experience, not only for Lisa, but also for her mother. Lisa learned about pride and sense of accomplishment. Her mother learned that Lisa was more prepared for her independence than she was.

It is an important story for every parent who should be making some very important decisions right now.

In a quote from the article, Mrs. Pender says, "The combination of giving Lisa her sense of independence and giving me time to go off where I want to without having to rush to pick her up is worth all the squirming I do."

It's true. . . "Children Learn — While Parents Squirm". All parents.

Reprints of the article are available by writing to The Exceptional Parent magazine, Psy-Ed Corporation, Room 708 Statler Office Building, 20 Providence Street, Boston, Massachusetts 02116.

Parable Turtles

Pete Young, Executive Director of Orange County AHRC, wrote this parable for "The Torch", the chapter's Newsletter. It was inspired by a State Association bulletin on the disparity between dollars spent for mental health and mental retardation.

Once upon a time, in the town of De-em-eich, there was a little zoo. In the beginning, the zoo was visited by all of the children and adults in the town regularly. They loved to see the ducks swimming on the pond, listen to the lions roaring in their dens, hear the gorillas beating on their chests. Because there was so much interest in the zoo, the Town Fathers spent thousands of dollars building new settings for all of the animals.

The zoo came to be famous. Not only did the townsfolk come, but visitors from all over the world. Architects begged to be allowed to design the new buildings. Those who ran the zoo began a wonderful program of reproducing the animals in captivity — and developed satellite programs throughout the surrounding countryside. More and more people came to work for the zoo. Not only regular keepers, but specialists who were interested in doing research and in expanding the program.

Special interest groups rapidly developed to support the finest of buildings and equipment. The Audubon Society pushed for the most modern and beautiful setting for the birds. The Feline Society was great for the big cats. Everyone had a pet project. Dr. Kohrabi, head of the zoo, listened eagerly to all of these groups, and pushed for the completion of the various projects. Unfortunately there was one small group who just couldn't get to first base with the doctor. This was a group who were interested in the turtles. And, most of the people in the town of De-em-eich agreed with the doctor.

The turtles were given a small piece of swampy land that no one else seemed to want. The original Turtle House became more and more run down. As much as the group hollered for money and better facilities, it made a very little impact. The turtles were lucky to get the left-overs. Finally the SPCARC stepped in with a law suit to prevent the continued neglect and cruelty to the turtles. Dr. Kohrabi and Mayor Huge agreed that something had to be done. So-called specialists were consulted — the computer wheels were spun — plans and more plans were developed. Of course, the turtles were still in the old Turtle House, although some of the overcrowding was taken care of by sending some of the turtles to buildings now abandoned by the other animals — but turtles in bird houses doesn't seem to make much sense.

And now we wait and wait and wait to see what is going to happen to the turtles. Some things are beginning to happen, but it is going to take the continued pressure from all of the turtle lovers.

A slap on the wrist

The former director of volunteer services at the Monroe Developmental Center was sentenced to one year probation for sexually abusing a retarded boy from the center.

The judge also ordered him to "have nothing to do with minors" while on probation. The judge harshly reprimanded the man, an Episcopal priest, during the sentencing.

The man was one of five originally charged with felonies during a June police investigation of alleged sexual abuse of retarded boys at the center. But those charges were reduced to misdemeanors by a county grand jury.

Printing dispute

ARC complies with Fair Labor Act

An article in the January issue of Our Children's Voice focused on a complaint by the commercial printers in St. Lawrence County that the Association for Retarded Children Rehabilitation Center paid "subminimum" wages to its sheltered workshop printing employees.

Since that report, the Federal Employment Standards Administration determined that the commercial printers' contention that government aid to the ARC, coupled with the ARC's legal ability to pay less than minimum wages, enable the ARC to submit low bids on printing

contracts, thus undercutting commercial printing establishments, has no basis.

Warren D. Landis, deputy administrator of the Wage and Hour Division of the Employment Standards Administration, said a survey last year of wages paid by the St. Lawrence County ARC revealed the workshop "was in substantial compliance with the Fair Labor Standards Act".

Landis said his agency's jurisdiction is limited to "assuring that the workshop pays proper wages to their handicapped workers". The printers had asked Rep. Robert C. McEwen to look into their charges of the ARC print shop undercutting them. McEwen forwarded the request to Mr. Landis' agency, but took no position on the truth of the charge himself. Landis said in his letter to McEwen that the State Office of Vocational Rehabilitation had given the ARC grants in 1973 and 1975 to purchase printing equipment. But Landis said his agency had no jurisdiction to respond to printers' charges that the government financed capital and operating costs for the ARC enabling it to undercut commercial enterprises.

He did say in the letter that it is legal to pay handicapped workers less than the minimum wage, depending upon their abilities, and that the lower wage must first be approved by the government.

The continuing controversy last bubbled to the surface a month ago when ARC representatives met with representatives of the county's Printers Association regarding the disagreement but failed to reach a solution.

Scholarship winner keeps in touch

Florence Hornbeck Acree, a former recipient of the Weingold Scholarship for college students in special education, wrote recently to Edward Licence, Chairman of the Scholarship Awards Committee from Fort Richardson, Alaska:

As I am a former recipient of the "J. Weingold Scholarship" to college students, I thought the Association would be interested in my post-graduation experiences.

In May, I moved to Alaska as the Army transferred my husband here.

You will be glad to know that the Association for Retarded Citizens of Anchorage (ARCA) hired me to work in their "Early Childhood Center." I am employed as a home-teacher. Using the Portage Project developed in Portage, Wisconsin, I make weekly visits to the homes of handicapped children to provide them and their parents with instruction.

My children's ages range from birth — 3 years. We're presently under a government grant — and hoping it will be renewed!

My job is truly exciting and rewarding. The Association here is an ever - growing project, so we're very proud of it. We are very lucky to have new, beautiful facilities — Classrooms, a preschool and sheltered workshop.

Thanks again for aiding me in my education. Without it, I would be missing the wonderful opportunity of working for ARCA!

Sincerely,
Florence Hornbeck Acree
(Class of '76)

We don't hear from many of our former scholarship people. When we do, it's always exciting to us — especially when they are buried up to their elbows in the field, as Mrs. Acree seems to be.

Program development grants authorized

Chapter 333 of the Laws of 1976, amended by Chapter 340 of the Laws of 1976, adds Section 11.37 to the Mental Hygiene Law and provides the Commissioner of Mental Hygiene with the authorization to make grants to local governmental units and voluntary non-profit agencies for the development costs of community residential facilities for the mentally disabled. The costs can be financed within specified categories to the limit of amounts appropriated by the legislature for this purpose.

Program development grants provide funds to begin the process of establishing

the residential facilities until such time as the other funding mechanisms become effective. Currently, the Commissioner is authorized to grant an amount not to exceed 80 per cent of the development costs.

To date, 17 program development grant applications totaling \$511,106 for the applicants' total start-up costs have been received in the Office of Social Rehabilitation. 80 per cent funding of these grants totals \$402,540. The Office of Social Rehabilitation is reviewing these applications and establishing procedures for funding.



Linda and Tom Gutkoska and John Paul

A real Christmas story

In April 1976, Tom and Linda Gutkoska accepted a foster child into their home. Little John Paul is a mentally handicapped child, a participant in our Albany Co. Chapter school. But Tom and Linda were able to look beyond that problem and see a child in need.

Something wonderful took place and the Gutkoskas just knew that they wanted to adopt this child. How wonderful it would be, they felt, if by Christmas he could truly be their child.

Let Linda tell it from there, as it was reported in the February 1977 issue of "Tax Chapter News":

John Paul's adoption went through court December 14, 1976. Our prayers were answered in so many ways.

The anticipation of Christmas was high in our house. No, not only for John Paul, but for Mommy and Daddy who wanted to

make this a truly memorable one for their son's first real Christmas in a family.

Christmas morning was an experience that is hard to put into words. John Paul had never experienced a Christmas morning, therefore he would have slept late, but Mommy could wait no longer than 7:00 a.m. to awaken him. John Paul came out of his room and was all excited to see the play village all set up, but had no comprehension all the other packages were meant for him. Mommy handed John Paul a package. First he'd kiss her, then Daddy, then he'd kiss the package. He enjoyed each new item, before going onto the next one.

Christmas, 1976, will long be remembered by us. The laughter and smiles will live in our memory, but most of all the gift of love will long be remembered.

More time for care standards

HEW's Social and Rehabilitation Services (SRS) has proposed to give Medicaid Intermediate Care Facilities certified for care of the mentally retarded (ICF-MRs) additional time to meet its staffing, safety and space requirements. Deadline for meeting standards will be extended on a facility-by-facility basis only if the delay will not hurt residents.

The proposed regulation would give ICF-MR homes up to an additional three years to meet the Life Safety Code requirements and standards for living units, dining rooms and therapy areas. Time extensions will be granted only if a home's written plan of correction is approved by the Secretary or his designee. The plan will be monitored by the HEW regional offices to assure that adequate and timely progress is being made.

The proposed regulation also modifies resident occupancy code requirements for homes caring for 15 or fewer residents. It permits certified rehabilitation counselors to be included among "Qualified Mental Retardation Professionals," makes requirements for maximum number of residents per room and minimum floor space per resident more flexible and makes a few technical changes in the regulation.

Proposed changes would help States overcome serious difficulties they are facing in meeting the current deadlines.

SRS held extensive discussions with the National Governor's Conference on Human Resources, the New Coalition, the National Association of Retarded Citizens, the Epilepsy Foundation, the Cerebral Palsy Association and the National Association of Coordinators of State Programs for the Mentally Retarded. The proposed regulation includes a number of recommendations that grew out of these discussions.

St. Lawrence opens three facilities

PRESIDENT PRAISES BUREAUCRATS

For once in their lifetimes, bureaucrats got a kind word and a pat on the back for something they have done right.

In her opening statements, made at the dedication of four new facilities for the county's handicapped, Kate Klein, president of the St. Lawrence County Association for Retarded Children, praised bureaucrats for their flexibility, their responsiveness and their sensitivity to people's needs.

"These are not the times for blessing bureaucrats, but today is a historic exception," Ms. Klein said at the opening of the new St. Lawrence County ARC Community residence at 2 State Street, Potsdam. "This community residence is visible evidence that bureaucracy can criticize itself, leave behind their rigid

ideas, and produce facilities which relate to the needs of the people being served."

NORWOOD FACILITY ALSO OPENED

Later the same day, officiating at the opening of two other new facilities for the handicapped — a community residence and a newly - renovated rehabilitation center, both on the site of the former St. Andrews school and convent in Norwood — Ms. Klein remarked, "If people are truly desirous of morality in government, as we constantly hear in the news, then this is a fine example of government funding supporting the moral decision to take our children out of institutions and assist them in entering community life."

OGDENSBURG FACILITY OPENS

At the dedication of the Ogdensburg facility, located on the site of the former A & P market on State Street, ARC President Klein's introductory statement commended those public servants "who act as a group in the same manner that decent people act as individuals".

"These training facilities represent tax dollars at work which every voter can approve of with enthusiasm," she told the assembled crowd of onlookers and dignitaries. "Facilities such as this mean that handicapped people are at last being served in a meaningful way towards a better life. It is also proof to voters that people who are not handicapped are being served by the funding decisions of these facilities. Because of the presence of St. Lawrence State Hospital here, Ogdensburg has always been a community particularly receptive to the unfortunate."

Teacher helps class learn full meaning of "retarded"

In 1973, Sandy Gart, a fifth grade teacher in the Merrick School system, thought it would be a good idea for her class to visit the Rosemary Kennedy School for trainable children. Since then, she has had one to three exchange visits a year.

An article by Mrs. Gart in Merrick Life vividly explained how the visits brought new understanding to her pupils. They learned that "retarded" doesn't mean what they once thought it did. Now they have certainties and not opinions. Now they saw the retarded as human beings as themselves and made strong new friendships. More, they learned to respond to issues affecting the retarded.

Shortly after Mrs. Gart's story appeared, Florence Flaton, president of the Bellmore - Merrick Auxiliary Association for the Help of Retarded Children, responded with this plea:

WHERE CAN RETARDED ADULTS LIVE?

One can feel nothing but a warm enthusiasm for Sandy Gart's program of having her classes visit the Rosemary Kennedy School for retarded children. What Mrs. Gart is doing to educate youngsters about the facts of retardation is a marvelous thing, and her story is a very beautiful one with its emphasis on giving, sharing, understanding and compassion.

But there is another facet to the problem of the retarded — what happens when the retarded child, whom everyone wants to help, becomes the retarded adult?

We in Nassau County are fortunate in having the Rosemary Kennedy School, in having the Association for the Help of Retarded Children, a non-profit organization which provides a clinic, a pre-school program, a camp and a school for children who are unacceptable at BOCES.

As for the retarded adults — AHRC has a facility where they can work for pay and attain dignity. There are also two hostels where 14 adults live, supervised, but independent. And that is all!

THE STORY DARKENS

The story of these retarded children, who are loved, cared for, cherished, becomes grim as they become adults, yet more than two-thirds of their lives will be spent as adults — what happens to them then?

The adult workshops are a solution, but the workshops cannot handle more adults than they have now. The obvious solution is to build more workshops, more hostels. Certainly, the people of Nassau County would make the money available through non-profit organizations. Why, then, are they not being built?

Hostels are wonderful for the dignity and well-being of our retarded citizens. Institutions are bad — everyone agrees on that. The Governor of New York State agrees: the professionals agree; the organizations agree; the parents agree — but the hostels are not being built.

"NOT ON MY BLOCK"

The reason is simple: it is the very common "Not on my block" syndrome. Everyone thinks it should be done — but do it somewhere else!

Sandy Gart is teaching her class that retarded children are very much like other children — that they respond to love, to kindness, to friendship, that they are not unaware of the world around them. The lucky ones in Nassau County grow up in this atmosphere of caring. And then, suddenly, they are 21 years old, or 18, or whatever the magic number is — and it's a cold world out there. The loving and caring and sheltering are finished and, for most of them, a lifetime of bleak despair begins.

On whose block, in whose neighborhood do we build the hostels? That could be the end of Sandy Gart's story — that the children to whom she is teaching compassion today may be willing, someday, to stand up and say "Build your hostels on my block!" But can we wait that long?

And here, reprinted in full, are the sensitive letters written by some of the children in Sandy Gart's class after reading Florence Flaton's article:

WE WANT TO HELP

I am one of Mrs. Gart's students. She read the article that you wrote in Merrick Life.

The people who don't want hostels on their block don't know how difficult life is for retarded children, and what friendly humans they are, and not much different from us.

I think more hostels should be built. I think people should be made aware of the problem. Maybe we should hold a meeting and invite some retarded adults to speak about this. Then people may become more concerned.

From
Adam Hird

I think that people should vote and get rid of institutions, because at least in schools they try to teach the retarded people how to live independently, and how to do things, but in an institution, they don't care and love them and they don't give them personal attention.

I also think that schools and hostels are GREAT! because they help the kids and they are nice to them and the people who work with them must have very good hearts.

I also think that it is too bad on the people who say "don't put that school or hostel for retarded kids here", because they don't think how much the schools and the hostels could help the kids and adults. People who don't have retarded kids don't really know how it feels to have a retarded kid. Think about this and the kids.

Sincerely
Steven Onbuck

I think your article about retarded people is excellent. I am in Mrs. Gart's class and she has told us a lot about retarded people, and that we should try to understand them, not just feel sorry for them. There should be more people like you, like Mrs. Gart and all the organizations for retarded people.

I think you should do more things to make people understand what it is like to be retarded and nobody likes you. A lot of people say they understand retarded people and they want to help them, but when the county decided to put up hostels they want them "somewhere else." I think people should start understanding in reality, not in their minds.

Sincerely,
Stefanie Helsig

Why doesn't anybody care? Is it because they don't really know about retarded people? Do they think retarded people are harmful and crazy or is it just that people don't want to take the time to know them? I think retarded people are fun to be with; they are loveable and kind. If everybody thinks institutions are bad, why do we have them? Why don't we have hostels for retarded people? Is it because no one wants retarded people near their homes? People care, but only in their minds. What could we do to make people care, care by giving and getting those hostels up? I will volunteer to talk to any group of adults who feel the same way. I would like to make others aware of this problem because I feel it in my mind. I feel it in my heart, I just feel it everywhere. I want to help. What can I do?

Sincerely,
Gary Lustberg

One teacher has given her pupils maturity and compassion beyond measure by simply starting out to show them what "retarded" means.

ARC exec welcome

The past few months have been truly busy ones for our ARC's in Delaware, Dutchess and Schenectady counties. The Boards of these three chapters have been interviewing candidates for the position of Executive Director. They recently made their final choices from among the many applications received from across the state, as well as from neighboring and nearby states.

All of us at NYSARC are pleased to welcome our newly appointed executive directors: Stepehn C. Helfgott, Delaware; Skip Weatherford, Dutchess; Carl Hawkinson, Schenectady. Here is some background information on our new directors.

DELAWARE COUNTY

Stephen C. Helfgott comes to ARC with a rich background and knowledge in Special Education programs and services. He has most recently been director of the Beaumont School in Liberty, N.Y. Steve is a native of NYC and received his degrees from the City University of N.Y. and Fairfield University in Connecticut.

SCHENECTADY COUNTY

Carl Hawkinson is a native of Wilmington, Delaware. He earned his BA degree in Sociology at Rutgers University, and his MS in Rehabilitation Counseling at West Virginia University. Recently, he has been assistant director of the Easter Seal Rehabilitation Center of Southeast Connecticut. His previous work experiences include workshop director as well as executive director for the New Jersey ARC.

DUTCHESS COUNTY

Skip Weatherford is a native of Omaha, Nebraska. He received his BA degree from the University of Nebraska in Education. He spent 8 years in a private school for disturbed children. Prior to his position now for the ARC, he served as Supervisor of Vocational Rehabilitation Services at the Hudson River Psychiatric Center.

On behalf of our statewide membership, we know you join us in extending best wishes to these gentlemen. We look forward to a long mutually rewarding relationship resulting in good things happening for the mentally retarded in Delaware, Dutchess and Schenectady counties.

Our Children's Voice
Retarded Children Can Be Helped

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