

Allegheny Accents

a bimonthly newsletter from the **ALLEGHENY COUNTY
CHAPTER**

Pennsylvania Association for Retarded Citizens, Inc.

July 1976

1001 BRIGHTON ROAD Pittsburgh, Pennsylvania 15233 telephone: (412) 322-6008

ALLEGHENY COUNTY URGENTLY NEEDS ALTERNATIVES TO INSTITUTIONS

Mary Wilson, the parent of an 18-year old son who requires 24-hour a day supervision, asked the Allegheny County Chapter to organize a meeting to answer for her and other parents who keep their retarded son or daughter at home one overwhelming question: what will happen to my dependent child when I die?

The meeting was held on June 26th, attended by nearly 300 parents and the Secretary of the Public Welfare Department, Frank Beal. For two hours the parents demonstrated the need for more alternatives to state institutions by revealing to Secretary Beal their family's needs.

Many of the situations that parents described were "urgent", "critical", "immediate", and "desperate". Other parents were worried about what would happen to their son/daughter when they (the parents) die.

The parents generally were frustrated and/or angered at the state DPW for failing to develop alternatives to institutions at a reasonable rate. Robert Matesic, ACC-PARC President, told Mr. Beal:

"We plead with the government of the State of Pennsylvania through the Department of Public Welfare to provide our children with a decent place to live and learn to avert their possible warehousing in an institution when we die. We don't want just a bed and a roof for our sons and daughters. We want a clean, sanitary, safe, comfortable living arrangement with the type of constant supervision and advice we've given our children all their lives."

ACC-PARC distributed a paper entitled "Pretty Words? Or a Real Commitment? State Officials Talk About Alternatives to Institutions". Interspersed between the Governor's and Welfare Secretary's proclamations favoring community living were these facts:

(1) the state funded only one new group home for the county in the last year;

(2) the state is funding no new group homes for the county in the next year;

(continued)

(continued)

(3) during the last year the state funded no new foster homes in Allegheny County;

(4) according to the state's plan, the county has received \$1 million less for community living than was promised. This means 100 less people are being served than planned;

(5) there is a shortage of adult training programs in the county. Nearly 200 individuals are sitting at home awaiting the start of new sheltered workshops or adult activity centers;

(6) there is no place for people to go who need residential care. Admissions to Western State School and Hospital are closed. Private institutions are filled and no alternatives are being built.

Parents, not wanting to hear any more "pretty words" from the state, had invited Secretary Beal to listen only, not to speak. The co-chairpersons of the meeting, Marlene Burda and Mary Wilson, suggested to Mr. Beal that he respond through actions rather than words. They suggested among other ways that he might ask for a supplemental appropriation from the legislature for community services, make the five-year plan more ambitious, and cut some of the red tape.

At the end of the meeting Secretary Beal thanked the parents for sharing their needs with him. He stated, "I will stand on my words and those of my predecessors." The Secretary plans to meet again in September with the Allegheny County parents to tell them of the actions he has taken.

During the summer parents plan to meet within their own communities, to "organize their thoughts and their needs". Parents who are interested in volunteering to participate in these meetings are asked to call the Chapter office, 322-6008, or mail the return form contained in this issue of the Accents.

Several legislators also attended the meeting, and expressed their appreciation for the manner in which the parents publicly voiced their concerns: "anger and frustration, yes, but not arm-waving hostility". (NOTE: legislators attending were Senators Early and Romanelli, Representatives Abraham, Caputo, Ravenstahl. Rep. Fisher sent a representative.)

After the meeting, Mary Wilson knew one thing for sure .. most parents share her concern for her son's future. As one parent said, "My heart goes out to all of us."

Yes, I would like to participate in meetings to discuss needed alternatives to institutions.

NAME _____ PHONE _____

ADDRESS _____ ZIP _____

Please return promptly to ACC-PARC, 1001 Brighton Rd., Pgh., Pa. 15233, or call 322-6008.

*** OUTSTANDING VOLUNTEER AWARDS ***

Presented June 5, 1976
on "A Special Evening",
Installation & Awards Dinner

Mrs. Joseph Falvo, Chairman
Norman Lazarus, Co-Chairman
Mrs. Raymond Scannell

S. ASHER WINIKOFF, ESQ.

... as Outstanding Advocate, especially in the area of the Right to Education decree. "He is sensitive to the needs of people who are mentally retarded and has served to assure them of their equal rights. He has enabled them to receive the education to which they are entitled. He has spoken in their behalf."

MARLENE BURDA

... as Parent of the Year. She has devoted her energies to the betterment of the world for children and adults who are mentally retarded; has traveled throughout the state monitoring conditions in residential facilities; has been outspoken in demanding the rights of retarded citizens. Presented "on behalf of all those whom she has served and whose lives have been enriched through her efforts."

COMMUNITY COLLEGE OF ALLEGHENY COUNTY/CENTER NORTH

... for outstanding educational programming in the area of developmental disabilities. Benefitting from these programs have been members of families, board and staff members, and retarded citizens themselves. "For significant contribution in community education."

JUNIOR CLUBWOMEN

... 3,000 members of the 27 clubs in the Junior division of the Allegheny County Federation of Women's Clubs raised over \$10,000 during the past 2 years to furnish and equip the North Side Developmental Center. With mental retardation as their Director's special project, the Juniors "furthered their many years of commitment to ACC by continuing to serve as volunteers and advocates."

CLIPPED WINGS ... for 5 years volunteer services and fund-raising activities demonstrating continuing interest in the growth and improvement of the North Side Developmental Center. "Year-round advocates within their communities, truly concerned about the futures of those we serve."

BETTY SCHRASS ... for outstanding volunteer services to Parc-way Industries/North. "A dedicated, trustworthy, dependable woman who has compassion and understands the needs of the employees."

DARLENE RIZZA ... as Outstanding Youth Volunteer. She is one of the leaders of the Hope Corps and has been a volunteer camp counselor for the past 2 years. "An invaluable asset to our program."

PERRY-HIGHLAND JUNIOR WOMAN'S CLUB ... for volunteer services to the North Hills Developmental Center for nearly 17 years. For "continuing generosity and continuing concern of members who have given so willingly of their time, their talents and their affections."

LOUIS SLAIS .. for Special Services. Mr. Slais' award recognizes his three-fold contribution: as President of Pittsburgh Brewing Company (ACC's "box factory" assembles cases for the brewery); as a member of ACC's Board of Directors; as a member of PARC-way Industries' Advisory Board. "He has been concerned with the overall development of Chapter resources and programs."

BELL OF PENNSYLVANIA and WESTERN ELECTRIC CO., INC. ... for contributing toward the growth and development of Parc-way Industries/East. "In recognition of their contributions in developing work skills and providing meaningful work opportunities and for their confidence in the abilities of workers who are mentally retarded."

*** BICENTENNIAL BIKE/HIKE AWARDS ***

Despite the fact that rain and tornado-like winds forced Allegheny County to cancel or curtail events in some locations, ACC-PARC had the most successful Bike/Hike in the entire state!

For this success we thank our Chairman, Rocky Bleier (who carried his 2-year old daughter, Samantha, on his back for 10 miles), 30 local celebrities (radio and TV personalities and Pittsburgh Steelers), 57 organizations who coordinated and helped at local bike/hikes, 50 police and fire departments, the 28th Signal Battalion of the National Guard and the County Sheriff's Department, and 75 businesses and organizations who donated refreshments and prizes. Most of all we thank all who braved the wind and rain, biking and hiking in 33 rides and hikes held in 26 locations throughout Allegheny County, their sponsors, and the coordinators of each event. THANK YOU! Outstanding awards were as follows:

Worn Tread Award	Rocky Bleier
Outstanding Biker	Pat Cambridge
Outstanding Hiker	Leo McDonough
Outstanding Business	Smaller Manufacturers Council
Outstanding Group	Shaler High Bike Club
Outstanding Ride	Perry-Highland Juniors
Most Mileage	Robert Bondl, Kevin Heilmann, Mark Lugin, Tony Trosan, Craig Young
Outstanding School	J. A. Allard Elementary
Outstanding Student	Carol Derrick, Keystone Oaks



(Awards were given according to money received at ACC-PARC office by May 20, 1976.)

**20,000
NEEDED**

Will you join the 20,000 men and women in Allegheny County who will distribute literature and accept contributions during our annual door-to-door fall fund drive campaign?

You will be helping to obtain funds vitally needed to continue ACC's programs of advocacy and direct services. And you will help to inform the public about what the Allegheny County Chapter is and does. Just think .. three of the ten families you visit on your street may be in need of this information: for themselves, for a relative, for a friend.

Please volunteer. By helping us, you are helping people who are mentally retarded to receive the services they need and deserve.

Jean Dawson
Fund Drive Coordinator
Call 391-0187 or 322-6008

THANK YOU ...

from the North Area Developmental Center to Mellwood Women's Club .. to friends in Easter Seal classes .. to Shrine clowns .. to the senior citizens from the Corbett Apartments .. to the friends who provide such enjoyment and companionship to the children all during the year.

**YOU ARE
WELCOME ...**

to attend meetings of the ACC Board of Directors. However, the schedule for summer meetings has not yet been finalized. If you are interested, please call the Chapter office to make certain of the date and time of the next meeting.

ADVOCACY NEWS

ROBERT NELKIN
ASSOCIATE EXECUTIVE DIRECTOR

SON DISMISSED FROM INSTITUTION BECAUSE OF PARENT

A young man was dismissed from a state-licensed and funded residential facility because his parent persistently questioned the care and training the son received from the institution. The dismissal of the young man to his parent's home followed subtle threats and intimidation from the facility's administrators that, "If you don't like the program, take your son out".

Getting rid of children of parents who are "trouble-makers" may be one of the cruellest actions that can be taken by an institution. Yet none of us stopped this cruelty. Not the other parents, the local MH/MR Center, the County MH/MR office, the Department of Public Welfare, or this Association.

Until we do stop intimidation and the getting rid of children of questioning parents, the question will remain, "Who is next to go?"

INSTITUTIONS: MANY CHANGES AND NO CHANGE

Admissions to Western State School and Hospital are closed. Polk has decreased from 2,750 to 1,950 residents in just two years.

The Superintendents of Polk and Western were fired. Numerous evaluations and consultant reports have been filed. Both facilities are trying to develop good training programs.

In other words, many changes for the better have occurred.

HOWEVER .. we recently visited Polk and Western for one day each and found no change in one of the most important areas: tender-loving-care. In two whole days of visits, we saw only a few of hundreds of the staff we observed giving personal attention to the residents.

Why couldn't the staff have talked to the boys and girls when they were feeding them? Couldn't someone have pushed a boy on the swing instead of watching him like prison guards do? Where were the reassuring words and physical touching? Couldn't the staff have tried to stimulate activity and help the residents grow and learn?

We think all of this should be happening since the working conditions are improving. We praise those workers who care about the residents and give them attention and tender-loving-care. We challenge the workers who don't. A lot more needs to be done!

PARENTS IN OTHER STATES RECEIVE SUBSIDY PAYMENTS

New York and Minnesota are beginning subsidies to families to assist them in maintaining their retarded child at home.

The experimental program in Minnesota grants monthly subsidies of up to \$250.00 per child. The child must be (1) under 18 years of age and (2) eligible for placement in an institution. The program in New York is similar to the Minnesota program. It was ordered by a Federal Court Judge to help improve conditions at Willowbrook State Institution.

A radical idea? Well, why not? Family care is less expensive to the taxpayer than institutional care would be. And the children receive the love and attention missing in most institutions. Anyone want to start the ball rolling in Pennsylvania?

EAST AREA PARENTS ORGANIZE .. MORE TRAINING PROGRAMS FOR ADULTS

Eighty parents in the eastern suburbs organized in May and June to get another sheltered workshop started. They are doing this because their adult sons/daughters are sitting (or will be sitting after graduation) at home without anything to do.

The parents met with the Allegheny County Mental Retardation Administrator, Chuck Peters, to request that a sheltered workshop be started in the Penn Hills area. Peters praised the parents "for looking ahead better than the professionals do." But Peters was unable to make a firm commitment to the parents because of uncertainty about funds from the state.

The parents then met with Senator Majority Leader Tom Nolan and State Representative Ron Cowell. Both legislators promised to meet with the County Commissioners to help get the sheltered workshop started.

PARENTS TO RECEIVE REIMBURSEMENT OF OVERCHARGE BY INSTITUTION

In January we discovered that the State of Pennsylvania was discarding legislation which PARC sponsored. Senate Bill #53, when passed by the legislature and signed into law by the Governor, meant parents would no longer be required to pay for their son's/daughter's MH/MR services once they reached 18 years of age. But, the Department of Public Welfare ignored the law and charged some parents for their son's or daughter's room and board in an institution.

Through the help of our state association and Attorney Dane Ferleger from Philadelphia, the Justice Department informed the Department of Public Welfare that they (DPW) were breaking the law. DPW has finally agreed to pay back the parents who were illegally charged.

A parent from a local institution brought DPW's illegal action to our attention. We all are grateful to him.

PARENTS' R.I.P. CORPORATION DEVELOPED

Over the last months, some parents met to organize a non-profit corporation to act in their place, as surrogate parents, when they die. One of the parents said, "What I want from this corporation is to be able to Rest in Peace". Thus, the name.

The need for this corporation (R.I.P. Corp.) was stated by parents in various ways. (1) Other parents can best care for their son/daughter due to empathy; (2) the future of their sons and daughters should not be left to government due to lack of sensitivity; (3) siblings should not be burdened with the responsibility of the dependent person's care; (4) bank trust officers will gladly be relieved of tough decisions about the dependent person (banks will still make investment decisions).

Some ideas for how R.I.P. Corp. will work are: (1) corporation will advise bank on the use of funds and the care of the person; (2) corporation will be the individual's advocate; (3) corporation's money will supplement care provided by government agencies; (4) family's home will be willed to the corporation to be the residence of the son/daughter and others.

Many other ideas are being considered. We'll keep you informed of R.I.P. Corp.'s development.

IF YOU WOULD LIKE TO JOIN ANY OF THESE EFFORTS, OR
HAVE ANY QUESTIONS, CALL THE ACC-PARC OFFICE, 322-6008.

GOVERNOR CALLS CONFERENCE ON THE HANDICAPPED TO BE HELD IN DECEMBER 1976 AT HERSHEY, PA.

In preparation for this Conference, Region V (which includes Allegheny County) will hold a pre-planning conference on August 15. Five major areas of concern are to be discussed and priorities decided upon. It is important for all of us to make our needs known. Our voices will be a part of the voices raised by all other major areas of the handicapped such as multiple sclerosis, cerebral palsy, blind, etc. Be sure that your needs, the interests of the retarded, are included.

Our Region will have 75 delegates to the Hershey Conference representing all of the disabilities. Of the 75 delegates, 50% must be represented by handicapped individuals themselves; 25%, parents, siblings, or guardians of handicapped individuals; and 25%, other providers and advocates. It would be important to include in your reply, on a separate letter, your protest that since the mentally retarded will be unable to act as their own spokesmen at this conference, consideration should be given for increased representation by parents or other advocates for the retarded.

The State Conference has funds for registration and meals, but no funds are available for transportation or hotel accommodations. The state will attempt to raise money through private donations for scholarship funds on a need basis. WE URGE YOU TO WRITE YOUR STRONGEST STATEMENT POSSIBLE TO YOUR ELECTED REPRESENTATIVE AND THE GOVERNOR: TELL THEM THAT NEITHER YOU NOR YOUR SONS AND DAUGHTERS CAN ATTEND UNLESS ALL EXPENSES ARE PAID.

The following five areas and their 25 subdivisions are to be covered at the Conference. Please review them carefully and list your concerns and comments, according to your priority.

HEALTH CONCERNS: 1) Research, 2) Technology, 3) Diagnosis, 4) Prevention, 5) Treatment.

SOCIAL CONCERNS: 1) Attitudes of the General Public Toward Handicapped Individuals, 2) Psychological Adjustment of Handicapped Individuals and Their Families, 3) Recreation, 4) Participation in Cultural Activities, 5) Architectural Accessibility, 6) Transportation Accessibility, 7) Communications: Techniques, Systems, Devices.

ECONOMIC CONCERNS: 1) Employment, 2) Economic Opportunity, 3) Economic Security.

EDUCATIONAL CONCERNS: 1) Preschool (0-5 years), 2) School Age (5-21 years), 3) Post School (21 years plus).

SPECIAL CONCERNS: 1) Problems of the Severe or Multiple Handicapped, 2) Community and Residential Based Housing, 3) Service Delivery Systems, 4) Civil Rights of the Handicapped, 5) Unique Problems of Handicapped Minorities, 6) Unique Problems of Disabled Veterans, 7) Unique Problems of the Handicapped Aging.

Select your priority from only those 25 subdivisions that you feel pertain to your needs. The return form is printed on the next page of this issue of the ACCENTS. If additional space is needed, please attach the form to another sheet of paper.

Return the form to Norman Lazarus, ACC-PARC Board Representative, c/o ACC-PARC, 1001 Brighton Road, Pittsburgh, Pa. 15233, no later than August 10, 1976.

CONFERENCE ON THE HANDICAPPED .. REPLY FORM

Return to Norman Lazarus, ACC-PARC, 1001 Brighton Rd., Pgh., Pa. 15233 by Aug. 10.

NAME _____ PHONE _____

ADDRESS _____ ZIP _____

In order of priority, my areas of concern are:

1. _____
2. _____
3. _____
4. _____
5. _____

If additional space is needed, please attach this form to a separate sheet of paper.

ABATEMENT OF LIABILITY

In the bulletin from Secretary of Public Welfare Frank Beal, the following information was distributed throughout Pennsylvania on March 26, 1976:

"I am ordering the abatement of liability for an initial Psychological Evaluation (e.g., tests, batteries, etc.) performed by Base Service Units whenever the source of such recommendation involved a 'Due Process Hearing' case. The responsible public school district/Intermediate Unit will verify such requests. These will only be honored when performed in the established procedure by Base Service Unit personnel or contracted personnel."

Bill Casile, Compliance Officer
Right to Education

"CRAFTY CREATIONS"



If you are involved with scouting .. or Bible school classes .. or just want some projects to keep the kids busy on a rainy day .. this book is for you. If you like to make your own holiday decorations or need ideas for centerpieces or favors or want to make something decorative out of odds and ends you have around the house .. this book is for you.

Junior Clubwomen developed nearly 90 pages of "Crafty Creations" and the entire proceeds go to ACC-PARC. To order, send \$1.00 plus 50¢ per copy for postage and handling to ACC-PARC, 1001 Brighton Rd., Pgh., Pa. 15233.

Mary Lou Magistri
Resource Development Coordinator