



ARC
Pennsylvania
Historical
Overview

**Association for Retarded Citizens,
Pennsylvania**

Historical Overview

1949 to 1990

Over 40 years of parents caring and sharing
for the benefit of their sons and daughters.

Edited by Linda H. Drummond

This historical film and booklet were made possible by the generous support and encouragement of Teddi Leiden, ARC member from Hollidaysburg, Blair County, Pennsylvania. The Association and its members sincerely thank Teddi and are grateful for her enthusiastic endorsement and assistance with this endeavor.

For additional information contact your local ARC (Appendix E) or the ARC, Pennsylvania, 123 Forster Street, Harrisburg, PA 17102. Phone: 1-800-692-7258.

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INTRODUCTION

"ETERNAL VIGILANCE IS THE PRICE OF FREEDOM."

Thomas Paine

How proud we are to tell the story of the Association for Retarded Citizens, Pennsylvania. The history of the ARC has been created by parents, each one having a story to tell and these stories blending to make the ARC story.

The history of the ARC is the result of parents who were willing to speak out and work on behalf of not only their son or daughter, but every person with mental retardation. Parents devoted their lives promoting this movement. For example, when you read about the monitoring of institutions during the 1950's, 60's, 70's, and 80's you will find that there were parents who crisscrossed the state documenting the inhumane and dehumanizing conditions of the institutions - conditions that we must never forget. These institution reports triggered the court cases that have made such a difference in the lives of people with mental retardation.

For those of you who have been involved in the movement for any length of time, this history will bring back many bittersweet memories of battles lost and won; for those of you just entering the movement, whether family or friend, we hope it will inspire you to maintain the accomplishments of the past and to work diligently for an even brighter future - a future which can only happen with your personal commitment of time and talents.

It was the advocacy of many parents and friends that brought the movement to where it is today. It is this strong, never ceasing advocacy, which now includes consumers, which will enable this wonderful, challenging, demanding, exciting movement to move forward.

*Teddi Leiden
Parent and Advocate*

ARC, PENNSYLVANIA HISTORICAL OVERVIEW

In the early 1900's and before, children with mental retardation were not accepted in schools and had nowhere to go. Adults with mental retardation had nowhere to go either. Parents were having a bad time, too. In 1949 Florence Schwartz (deceased) wrote a letter to a Philadelphia newspaper asking other parents to come to a meeting to address concerns and ways to handle the community's fears about persons with mental retardation. Eight people responded. The early meetings were held in the office of Yale and Juliet Nathanson, a psychologist and a physician.

Following a public meeting held by this group in Philadelphia, at which Pearl Buck, nationally known author, was the speaker, parents from Montgomery, and Bucks County became interested. More and more parents from Philadelphia and nearby counties joined the group and it was decided to form a statewide organization with county chapters. A new constitution was written and the Philadelphia members gave up their name to the new state association - Pennsylvania Association for Retarded Children. Samuel Goldman was elected president; Irving Koff, treasure, and Bernice Perrick, Secretary. Photographer Robert Hayman ran the first advertising/fund raising campaign with Johnny Goldman as poster boy.

On October 17, 1949, the Pennsylvania Association for Retarded and Handicapped Children was formed by a group of parents who were frustrated with the lack of services for their children. Their goal was to promote the general welfare of children with mental retardation, further education and training for professionals, promote public information and encourage formation of local chapters.

Their stated purpose was as follows:

To obtain the necessary legislation for the establishment, construction and maintenance at the public expense for free public schools and free institutions in the cities, towns, boroughs and villages, and to be staffed by teachers, instructors, physicians, psychiatrists, psychologists, neurologists, or any other person licensed by the Commonwealth of Pennsylvania to practice any of the medical professions, as well as nurses and other persons especially trained for the purpose of aiding, guiding, instructing, treating and rehabilitating children who are mentally retarded, blind, crippled, deaf, the victims of cerebral palsy, and who may be afflicted in some such similar manner regardless of their race, creed, color or national origin. After the legislation aforementioned is obtained and implemented, to aid such schools and institutions as far as possible.

This was the genesis of the Association for Retarded Citizens, Pennsylvania. Today, this non-profit, charitable organization has over 14,000 members in over 50 county chapters.

The 1950's

The emphasis in the field of mental retardation in the 1940's and before was institutionalization. Put them away and provide care giving. The 1950's brought an emphasis on keeping families together. This developed a need for community services and family support.

In 1950, all children with IQ scores under 50 were exempted from the public school system and assigned to the Department of Welfare. In addition, any child who was deemed "unable to benefit from classroom instruction" could, by Public School Code, be exempted from the public school system. Providing services to these children was one of the earliest activities of the association. At first, informal sitter services were offered by parents to each other, but soon classes for the "orthogenically backward," sometimes called "Opportunity Classes" were established throughout the state.

In an expression of concern for the welfare of children in the three state-operated facilities for the mentally retarded, Polk, Pennhurst, and Laurelton, a Sunshine Committee was organized for the purpose of sending cards and gifts to residents at these institutions. This effort met with resistance on the part of the institutional staff who would not provide the names of residents because of the violation of privacy this would incur. PARC sent the cards and gifts, unaddressed, and the staff distributed them.

Although state institutions had a permissive policy with regard to parental visits at this time, private residential facilities, for the most part, prohibited parental visits for the first three months after placement of a child in an attempt to sever parent-child relationships, a policy reflecting common professional advice to "put your child away and forget him/her."

Legislation passed in 1954 permitted public school districts to provide classes for children with IQ scores under 50. PARC members took immediate and active advantage of this legislation, persuading local school districts to provide space, and assisting in every detail of the arrangements for these classes.

1955 was a year of mental health reform in Pennsylvania. Tours of the state institutions by Governor Leader and members of PARC revealed severe overcrowding and waiting lists were lengthy. Nine thousand children were in institutions, three thousand were on waiting lists, and seventy applications for residential placement were being received each month. Expansion of residential facilities seemed the obvious solution. Legislation was passed in 1955 permitting the establishment of state supported interim care facilities for mentally retarded individuals on the waiting lists.

By 1955, 41 local chapters had affiliated with PARC. Standing committees had been established in the areas of Education, Legislation, Institutions, Organizations, Fund-raising Publicity and Public Relations, and Recreation.

In January of 1956, HB 1671, an appropriations bill which provided money for the building of three new institutions for the mentally retarded, was pending. It was known that the Senate intended to cut \$40,000,000 from the welfare budget, seriously jeopardizing this program of construction. PARC urged its members to contact their local legislators concerning the budget and itself sent telegrams voicing PARC's position:

Senator: NEWSPAPERS REPORT YOUR DISCUSSING CUT IN GSA BORROWING EXTENSION. REMIND YOU PREVIOUS ADMINISTRATION RECOMMENDED CONSTRUCTING THREE INSTITUTIONS FOR MENTALLY RETARDED NOW INCLUDED IN WELFARE DEPARTMENT REQUEST TO GSA. FOUR THOUSAND MEMBERS AND WIDE CIRCLE OF INTERESTED CITIZENS ALERTED TO NEED FOR INSTITUTIONAL CONSTRUCTION WATCHING WITH KEEN INTEREST. URGE NO CUTS IN WELFARE DEPARTMENT REQUEST.

PARC's efforts met with success and the appropriations bill passed uncut.

It was not the only victory for PARC in 1956. In March, Act 429 was passed, mandating the public provision of education for all mentally retarded children.

Evidence of the inadequacy of institutional care of children with mental retardation was tragically provided in the fall of 1957 when an influenza epidemic struck and caused the death of many Pennhurst residents. Upon investigation, PARC discovered there was no immunization program for state institutions. At PARC's insistence, the Department of Health and the Department of Welfare instituted immunization of all residents.

Stung by the events of a year in which the needs of children with mental retardation were ignored, forgotten or eclipsed by mental health, the need for a written statement from the Commonwealth on plans for persons with mental retardation seemed clear. Such a plan was requested by PARC of the Department of Welfare, and it was reported that this Department was writing such a plan in December of 1957. PARC decided, initiating what was to become a pattern, to prepare its own general statement of needs throughout the Commonwealth. PARC suggested to the Commonwealth that a separate state division to meet the needs of the mentally retarded was a necessary part of any plan. If a separate Department of Mental Health were established as a result of the proposed merger of the Department of Welfare and the Department of Public Assistance, there must be a separate division on Mental Retardation.

The 1960's

The 1960's increased attention to social programs and societal improvements included an increased awareness of philosophies dealing with mental retardation.

In 1960, the Federal Government stepped into the funding picture for human services. Federal legislation had been introduced in support of "Independent Living." The monies available from this bill were intended to assist the states in providing for their handicapped citizens greatly improved programs for the evaluation of rehabilitation potential. This funding would make possible rehabilitation services to handicapped individuals who formerly had been excluded from such service because they were not potentially employable. HB 611 had been introduced to the Pennsylvania General Assembly which would enable the State Vocational Rehabilitation Bureau to participate in this federal program. Subsequently passed as Act 85-A, the Act made \$240,000 available to Pennsylvania for the operation of sheltered workshops.

A 1965 expose on institutional conditions, "Christmas in Purgatory" by Burton Blatt, a Syracuse University professor and Fred Kaplan, a photographer, greatly increased the country's awareness of existing conditions at our institutions. After this expose, ARCs initiated their push for deinstitutionalization.

The Associations for Retarded Children were organized to emphasize that parents could keep their sons and daughters at home in the mid 1960's. ARC played an advocacy role, pushing for community support services for families and individuals. This started to change after the 1966 MH/MR Act. The 1966 MH/MR Act was the first time monies were set aside for community services. By the late 1960's ARCs started to focus on legislative and legal issues. These concerns arose from the increased need for services, normalization and individual needs, as well as concerns which generated from the infancy of the statewide MH/MR systems. As the ARC's members became more aggressive and focussed on legislation they realized much of this legislation did not accomplish what was needed to serve this population.

On December 10, 1969, the Liens Bill passed the State Legislature. This bill, which was actively supported by the ARC, removed the burden of property liens against parents of children in institutions who were unable to pay the full cost of care. Until this time, some families were unable to sell their homes because of the old policy.

Since its inception, PARC had struggled to have the needs of persons with mental retardation considered separate from and equal to the needs of the mentally ill. The battle to prevent mental health from obscuring the distinct service needs of mentally retarded individuals was to be played out again and again. The establishment of a separate state Office of Mental Retardation was viewed as a prerequisite to the accomplishment of this goal. Efforts to persuade the Commissioner of Mental Health of the validity of this need met with failure. The Department of Mental Health in 1963 was divided into four Bureaus: Mental Hospital Services, Mental Health Services for Children, Community Mental Health Services and Mental Health Research and Training.

A welcomed reversal of the state's position on this matter came with the appointment of Arlin Adams to the position of Secretary of the Department of Public Welfare in the same year. Secretary Adams stated that he was prepared to create a Bureau of Mental Retardation within the Office of Mental Health to coordinate services provided by existing state agencies to the mentally retarded. Upon questioning as to the possibility of establishing an Office of Mental Retardation, Mr. Adams replied that a Bureau could be established through Administrative Action, but an Office would require statutory amendment. He conceived, however, of the Bureau as a steppingstone to such an Office. The Bureau of Mental Retardation was created through administrative action in 1964.

In June of 1968, a film entitled "Suffer the Children" was shown on a local TV station which movingly portrayed and publicly exposed the inhumane living conditions children at Pennhurst State School and Hospital experienced. At the urging of the local chapters and upon receipt of a letter from the President's Panel on Mental Retardation, PARC conducted an investigation of Pennhurst. In October a meeting was held with the Commissioner of Mental Health, demanding the immediate dismissal of the superintendent of Pennhurst, an immediate upgrading of the status of attendants, and a hold on the Commonwealth's proposed capital expenditure of \$5 million to build a 300 bed facility at Pennhurst. If these demands were not met by November 11th, a press conference would be held. There was no response from the Commissioner. The GSA granted the necessary loan for construction. The press conference was held. Resolutions came in to PARC headquarters from local chapters protesting the deplorable conditions at Pennhurst and calling for action.

The Kennedy Foundation made a \$25,000 grant to Pennsylvania to conduct visits to all Commonwealth institutions by PARC and the Jaycees. In November these grim and shocking visits began. "They could not believe what they saw", stated the residential care chairperson. "Some of them vomited."

In response to the exposed conditions and in an attempt to focus public attention on the situation, the Youth Committee of PARC organized a pilgrimage to Pennhurst in which 1000 youths participated throughout the state on November 29th. Each carried an ignited "candle of hope" to Pennhurst and returned to their communities with petitions of concern.

Visits to residential facilities throughout the state revealed that deplorable institutional conditions were not confined to Pennhurst.

IN 1969 the ARC membership adopted this Bill of Rights:

BILL OF RIGHTS FOR PERSONS WITH MENTAL RETARDATION

- The right to religious freedom
- The right to dignity, privacy and humane care
- The right to an individual program
- The right to unrestricted communication
- The right to own property, especially clothing
- The right to receive education and training
- The right to recreation and good physical fitness
- The right to receive prompt and appropriate medical treatment
- The right to be free from physical restraint.

Needs of Persons with Mental Retardation:

- to have opportunities to exercise their equal rights and liberties
- to make their own individual choices
- to be allowed to take risks in their decisions and actions
- to live in and be exposed to the community
- to be trained in skills necessary for community adaptation
- training to meet personal needs
- to have access to generic services
- to have specialized services when necessary

The 1970's

In the early 1970's ARC started court litigation to seek correction of some of the problems in the mental retardation field.

In 1970, parental liability for day programs and workshops was eliminated due to the ARC pressure. The key Pennsylvania litigation was the Right to Education case referred to as the PARC Consent Decree. What is the Right to Education? A class action lawsuit is an appeal for relief brought on behalf of one or more named individuals and all persons in the same jurisdiction suffering the same abuses. It was a new tool for advocates of persons with mental retardation. This litigation began in 1969. Attorneys for the Pennsylvania Association for Retarded Children (PARC) argued that equal protection under the law, guaranteed by the Fourteenth Amendment to the Constitution, required that all children

have equal access to public education and that they also have the right to due process of law. They based many of their arguments on the Supreme Court's ruling in Brown v. Board of Education in 1954, that separate educational systems do not provide equal educational opportunity.

The Commonwealth agreed to search for every child with mental retardation in Pennsylvania and offer each a public education. In order to make its decree effective, the court appointed two "masters" or experts in mental retardation, one with a background in education and the other with a legal background, to oversee administration of the program and report on progress. Pennsylvania also set up a Right to Education office to handle special problems and, especially, to conduct due process hearings. Pennsylvania's Right to Education office estimates that between May, 1972 and June, 1973, 10,000 children were placed for the first time in public schools. Of these, 2,551 were severely or profoundly retarded and 200 new classes for severely handicapped children were started.

In 1972, the final right to education stipulation, a consent decree between the ARC and the Commonwealth of Pennsylvania, was signed. This decree, which guarantees a free public school education to all school-age children, laid the foundation for the federal law providing for individualized education programs for all handicapped children. This was the first right to education law suit implemented because of the large number of children in the state institutions. This led to the development of the Intermediate Unit system for special education services and led to federal legislation.

Federal Legislation, Public Law 94-142 "Education for All Handicapped Children" was enacted on November 29, 1975. The contents of this legislation assure a free, appropriate public education for all handicapped children; protects the rights of handicapped children and their parents; makes states responsible for providing the education programs and seeing that the requirements of the law are carried out in every school district. This law requires the development of an IEP (Individualized Education Plan) for each child receiving special education. The ARC assisted in drafting and advocating for the federal right to education law. This legislation became P.L. 94-142, the Education for All Handicapped Children Act. The final regulations to P.L. 94-142 became effective October 1, 1977. Part of the foundation for this federal legislation is based on PARC's Right to Education Consent Decree which established the basis that all children are educable in one fashion or another.

In the early 70's there were few community programs for people with mental retardation. Twelve thousand individuals were served in large congregate settings called "institutions" or state centers.

The Commissioner for Mental Retardation reported to the Deputy Secretary for the Office of Mental Health. No one was responsible for community services. All staff were consultants to state centers and the primary emphasis was the maintenance and operation of state centers or institutions. Finally, in September of 1972 a separate office of mental retardation was established by Executive Order. Community services in existence received money primarily for vocational services along with consultation and education. Other than a financial relationship there was little partnership and planning between the counties and the state.

Amid an emerging national trend, the PARC played a major role in influencing change in

Pennsylvania's services to its citizens with mental retardation. The Pennsylvania Association for Retarded Children was a leader in advocating for positive change.

In 1972, the General Assembly appropriated \$1.7 million to support Pennsylvania's community residential program. What concerned them? The advocacy of PARC and its membership of parents along with the focus on state centers and the increasing awareness of dehumanization, victimization and poor conditions in state centers fueled this movement. The community residential program in Pennsylvania began in 1972 with the establishment of the community living arrangement programs.

Pennsylvania developed a continuum model; children's programs, adult programs and apartment programs. It was designed so an individual could move throughout the community. Community programs were large by today's standards: six to eight bed facilities.

By April of 1975, PARC's Plan for Community Services, complementing the Design for Living, had been completed. It called for the provision of a continuum of services for each Pennsylvanian with mental retardation based on his or her developmental needs. The service continuum included prevention and health care, case management, day training, home care, public education, recreation and social opportunities, job opportunities, residential services, personal and legal rights, personnel development, community education and religious activities.

The advocacy system for which Governor Shapp had seen an immediate need was finally initiated in 1972 when the Department of Public Welfare contracted with PARC to design and establish such a system. A staff person was hired to develop what was to be called the Pennsylvania Fellowship Plan.

In March of 1973, parents of institutionalized children received forms asking for their consent to use their children in programs of drug experimentation. In a cover letter sent with the forms, it was stated that PARC endorsed these programs. PARC, however, had not endorsed such a program and statements of their position in opposition to drug experimentation with the residents of institutions, were immediately sent to the Secretary of Public Welfare, that Department's General Counsel, the Director of the Governor's Health Service, and the Attorney General of the Commonwealth. In a telephone marathon to parents, institutions and public agencies, it was discovered that such experimentation had been going on for years and that there were no established guidelines to govern such programs. PARC asked its National Association to support them in asking for a nationwide moratorium on these studies. On April 9, a moratorium on all such experimentation in state facilities was called by the Secretary of Public Welfare.

The opportunity to pursue the Right to Treatment suit which PARC had been contemplating since 1971 came in 1974 when Attorney David Ferleger of the Mental Patient Civil Liberties Project initiated a suit for money damages on behalf of several Pennhurst residents and their parents. PARC counsel was advised to enter the suit and expand it to a class action. The United States Justice Department also entered the suit and asked PARC to investigate incidents of abuse. On February 4, 1975, alleging adverse and dangerous conditions at Pennhurst State School, a class action right to treatment suit was filed by PARC counsel against Pennhurst officials and the Department of Public Welfare.

In 1973 the Pennsylvania Association for Retarded Children changed their name to Pennsylvania Association for Retarded Citizens. This more fully showed the association's emphasis on serving persons of all ages, regarding issues pertinent to all stages of living. Later the name was changed from PARC to nationally recognized ARC with the state or county name following.

In 1974, the Pennsylvania legislature passed Act 249 and parental liability ended for services mandated by the 1966 law.

Pennhurst State School and Hospital. In June 1968 the film "Suffer the Children," shown on a local television station exposed the inhumane living conditions of the children at Pennhurst State School and Hospital located outside of Philadelphia. After PARC's investigation of Pennhurst they requested the immediate dismissal of Pennhurst's superintendent, immediate upgrading of the living status and a hold on the state's planned expansion at Pennhurst. For the next several years PARC was instrumental in monitoring residential facilities across the state and implementing changes in these facilities (e.i. - Hillcrest (ICF/MR), Ridgeview, Polk).

On February 4, 1975, alleging adverse and dangerous conditions at Pennhurst State School, a class action right to treatment suit was filed by PARC counsel against Pennhurst officials and the state's Department of Public Welfare. This law suit, *Halderman v. Pennhurst* signaled the beginning of the deinstitutionalization movement in Pennsylvania

On January 23, 1976, a Right to Treatment Bulletin noted that preliminary hearings on *Halderman v. Pennhurst* had been held before Judge Raymond Broderick on January 7th. Motions made by the defendants included a move to dismiss the suit. On the next day PARC counsel filed an amended complaint naming new defendants including the Deputy Secretary for Mental Retardation, the County Commissioners and the County MH/MR Administrators for the five county area, and Mayor Frank Rizzo of Philadelphia.

On December 23, 1977, Judge Broderick handed down his decision in favor of the plaintiffs in *Halderman v. Pennhurst*. Among his conclusions were:

1. Mental retardation is not mental illness. It is a learning handicap, not a disease. Therefore every person with mental retardation can benefit from education and training.
2. Citizens with mental retardation have a constitutional right to education, training and care needed to improve their level of functioning.
3. Citizens with mental retardation in Pennsylvania have a right to "minimally adequate habilitation" guaranteed under Pennsylvania's MH/MR Act of 1966.
4. The Commonwealth of Pennsylvania and its counties are responsible for providing this habilitation.
5. Minimally adequate care was not provided at Pennhurst. Thus, both the state and the counties have violated state law.
6. Section 504 of the Federal Rehabilitation Act of 1973 prohibits discrimination on the basis of handicap.

7. **Persons with mental retardation have the same right to equal protection and equal services as other citizens, as guaranteed by the Fourteenth Amendment to the Constitution. Segregation and isolation from community services violated this right because services provided at Pennhurst were not equal to those available in the community.**

In 1976, the ARC Public Health Services Committee applied pressure to the Department of Health to implement the hypothyroidism screening program, a means of preventing mental retardation.

Also in 1976, the ARC assisted in drafting and advocating for the federal right to education law. This legislation became P.L. 94-142, the Education for All Handicapped Children Act. The final regulations to P.L. 94-142 became effective October 1, 1977. Part of the foundation for this federal legislation is based on PARC's Right to Education Consent Decree which established the basis that all children are educable in one fashion or another.

In December of 1977, the board of the Pennsylvania Association for Retarded Citizens made a decision to call for a House and Senate investigation of resident abuse, based on allegations and descriptions of conditions at Polk State School and Hospital by a staff attendant. The publicity helped to generate an investigation by Pennsylvania's Auditor General, which documented major problems in medical and other services at that facility.

The 1980's

The 1980's heralded a real push for educational integration. The earlier federal and state legislation provided initially the basis for educational programs in institutions and then into communities. The ARC, PA's view of mainstreaming and education programs is to provide an individualized educational program based on each child's individualized needs as determined by an IEP (Individual Education Plan). The IEP is written with coordinated input from the parents, teachers, and therapists. The educational setting should be in the child's neighborhood school in the least restrictive environment to allow interaction with non-handicapped peers for as much of the school day as possible.

In 1982, the ARC prevented the state from block granting special education monies. Placing the funds in a block grant would have eliminated advanced funding and permitted a reduction in special education appropriations at the local level. The ARC, with thousands of parents and advocates, opposed and blocked changes that would have stripped the nation's handicapped education regulations of their clout.

The 1980's public awareness emphasized normalization, independent and supported community living, competitive employment with on-the-job training. Prevention and public health issues are at the forefront with information on possible prevention of mental retardation by awareness of some of the known causes. These causes include the need for appropriate pre-natal care for pregnant women; no drinking of alcohol during pregnancy to prevent Fetal Alcohol Syndrome of the newborn; awareness of the dangers of drug use (prescribed and illegal) during pregnancy; risks of lead poisoning to everyone but especially to children age 5 and under; need for newborn screenings for all infants before 3 days of age. Phenylketonuria (1965) and hypothyroidism (1978) newborn screenings are required

by law. Use of bike helmets to prevent head injuries for children is part of a nationwide Safe Kids Campaign.

Public health concerns deal with access to appropriate medical and dental care for persons on limited incomes. Also, there is a concern about prescription and over-the-counter drug interactions for persons taking a variety of medications.

Deinstitutionalization continues to be a major emphasis of the ARC. The ARC is actively involved in litigation to assure that persons already in institutions are provided with quality living conditions with attention to individual needs and abilities. The ARC also strives to find alternative placements for children under age 21, emphasizing smaller family-like environments.

In 1981, the ARC fought to defeat legislation that would have weakened the state's Mental Health/Mental Retardation Act. The proposed bill eliminated the Commonwealth's obligation to serve mentally retarded people. This would have virtually prevented any future movement of institutionalized residents to community programs.

Richard C., et al v. John F. White, DPW, et al is a civil rights action on behalf of a class of persons with mental retardation who reside at Western Center, an institution for persons with mental retardation in Canonsburg, PA. In 1989 this suit was brought against the state Department of Public Welfare by ARC, Pennsylvania, ARC, Allegheny County and Pennsylvania Protection and Advocacy based on lack of active treatment as prescribed by law; unnecessary restraints, and failure to provide community services.

The move toward integrated community living includes a variety of community living arrangements from large Intensive Care Facilities for the severely handicapped to 6-8 person group homes with care givers to individual apartments. In 1986 the Family Living program was initiated. The state has started to emphasize meeting individual and family needs through a Family Support System. This has involved increased emphasis on community resources to enable the family to maintain their member with mental retardation at home and to enable the individual to remain in a family unit in the community to maintain as normal a life as possible.

The 1980's and beyond indicates an increased emphasis on Supported/Supportive Employment Programs. This concept emphasizes training individuals for competitive employment opportunities. A Job Counselor works with each client to: provide appropriate social skills; learn interview skills; assist in the job search; provide on-the-job training; evaluate the individual's job performance; provide continual support and re-training as needed.

Early Intervention Programs. The Education of the Handicapped Amendments of 1986, (P.L. 99-457) has two major components - Title I for infants and toddlers, birth through age 2; and Title II for preschool age children with handicapping conditions. The establishment of an Interagency Coordinating Council with the Department of Public Welfare handling Title I responsibilities and the Department of Education handling Title II, creates a unique opportunity for a comprehensive system of early intervention services.

ARC, Pennsylvania has been actively involved with the state's development and implementation of these Early Intervention services. ARC members have served on coordinating committees, provided testimony at hearings, and advocated for the appropriate development of related programs.

New issues have developed as a result of the movement to community and family living arrangements.

- Zoning battles have developed in communities trying to prevent the opening of group homes. State and local ARCs have fought cooperatively with other agencies to resolve these conflicts.
- Transition services and programs are needed to prepare students in educational settings to move into jobs and lives in the community and outside of the school setting.
- Family Support Programs are now a reality with funds and services available in each community to assist families in providing for their children at home.
- Family Living Programs provide a living option other than large group homes. They offer small family type residences for persons with mental retardation.
- Older persons with mental retardation are a growing concern. ARC is addressing the need for community services to care for aging persons who no longer have families to assist them and who have health care needs due to aging.

THE 1990'S AND THE FUTURE

Self advocacy will be in the forefront of the 1990's movement in the field of mental retardation. Consumers with mental retardation are speaking up about their individual needs and interests. The first international Self-Advocacy Conference was held in 1967. The issues addressed over 20 years ago about what they wanted in their lives were the same as most citizens - family, home, friends, jobs, a chance to show what they can do, a chance to be contributing members of the community.

Work Force 2000 is a program by the Department of Labor and Industry to plan for the employment needs of the next decade. With an anticipated labor shortage employers will find the need to actively recruit and train employees. Persons with developmental delays will be able to meet many of these needs. Continued emphasis on appropriate integrated education and effective job training will find an integrated job force.

Futures Planning will help in the development of individual support systems to enhance the daily lives of persons with mental retardation. This will also assist families in preparing their children for continuation of as normal a lifestyle as possible once the parents are no longer able to help. Futures Planning is the preparation of an effective plan for the future

care of disabled dependents. It is a carefully constructed series of directives designed to meet the individual's long-term needs.

The ARC's emphasis will continue with governmental affairs and legislation; litigation to protect and obtain appropriate services; advocacy for individuals and families; public education; and local chapter expansion.

- The future will see more individualized activities and fewer segregated group activities.
- The ARC's future may be in organizing generic community resources around each person's unique disabilities.
- The future is NOT large community living arrangements. The future is NOT sheltered work activities.

If current trends continue the ARC may primarily be organized around support services for families and independent living, supported employment programs, integrated alternatives and strengthening the role of the self-advocate.

Citizen advocacy is a crucial element to assuring full citizenship to persons with mental retardation. Citizen advocacy is a program of volunteer assistance by mature, competent citizens who represent the interests of the handicapped person entirely on his own merits, notwithstanding the expectations of the general community.

Key Elements of Citizen Advocacy

- * Voluntarism
 - * Legal authorization unnecessary
 - * Matching of advocate and "protege"
 - * Legal action possible, depending on resources of citizen advocacy office
 - * Public education
 - * Freedom from conflict of interest
 - * Concentration on needs of client and his expressive need for friendship or for a confidant
- (Source: M.R. Known and Unknown, Page 89)

We can accomplish together as one large unit, what can not be accomplished as one, lone individual.

In order for ARC to grow stronger and be heard by the public and our legislators we must be one large voice joined together in unity to improve the lives of our children and all citizens with mental retardation.

- Coming together is beginning --
- Keeping together is progress --
- Working together is success --

ARC needs everyone interested in creating a better life for handicapped individuals as a member.

Over 40 years of dedicated volunteer efforts have greatly changed attitudes and programs. But we still have much more work ahead for the future before persons with mental retardation will be fully accepted members of society. With your help these dreams will become realities.

APPENDIX A

PAST ARC, PA PRESIDENTS

A special thank you to those who have served the ARC, PA wisely and diligently in the past.

1949-52	Samuel Goldman
1952-54	Martin Papish
1954-57	Samuel Register
1957-59	Eleanor Elkin
1959-61	Gertrude Barber
1961-63	Paul Reed
1963-65	Gordon Pritham
1965-67	Eleanor Kephart
1967-69	Harold Nathan
1969-71	James Wilson, Jr.
1971-73	Patricia Clapp
1973-75	L. Steuart Brown
1975-77	Elsie Schmidt
1977-79	Teddi Leiden
1979-81	Elton Atwater
1981-83	John Boyle
1983-84	Karen Kelly
1984-87	Roger Grandy
1987-89	Charlotte Twaddell
1989-	Virgil Quirk

APPENDIX B

WHAT IS MENTAL RETARDATION?

Mental retardation is defined as impaired mental development which originates before or during birth or in early childhood. It results in a slowness or limitation in intellectual development, emotional or social development and in academic and vocational progress.

Mental retardation should not be confused with mental illness. Persons with mental retardation simply have a learning problem; they learn at a slower rate than other people.

Mental retardation can and does affect families in all parts of the world and on every level of the socio-economic scale. The condition affects more persons than all other handicaps combined, and three out of every one hundred children born this year in the United States will be or will become mentally retarded. Today in Pennsylvania there are over 350,000 persons with mental retardation. Counting their parents and others close to them, one out of 10 households in the Commonwealth has experienced mental retardation.

(Source: ARC, Pennsylvania brochure)

MEASURING INTELLIGENCE

The first attempts to measure intelligence in children by Binet and Simon in France in 1905 were brought to the United States and extended. Around 1915, Stern and Terman proposed the "intelligence quotient" (IQ), to compare a child's "mental age" as revealed on the tests, with his chronological age. By dividing mental age by chronological age and multiplying by 100, a number is achieved: the individual's IQ. Subsequently, a wide range of other tests for measuring intelligence have been developed, using other methods for obtaining an IQ. The most widely used is the Wechsler Series, applicable to both children and adults. The average score on intelligence tests is 100. How far above or below this number a person's score falls determines whether he or she is psychometrically "bright" or mentally retarded. *

The following chart shows the major levels of mental retardation and the IQ ranges that apply to each level, from two widely used intelligence tests.

<u>Level of Mental Retardation</u>	<u>Obtained Intelligence Quotient</u>	
	<u>Stanford-Binet</u>	<u>Wechsler</u>
(Borderline)	(69-84)	(70-84)
Mild	52-68	55-69
Moderate	36-51	40-54
Severe	20-35	25-39
Profound	19 and below	24 and below

**(Source - Mental Retardation: The Known & Unknown, Page 5)*

WHAT IS DOWN SYNDROME?

Down Syndrome was discovered in 1844 by Seguin and is named after Langdon Down, who reported in 1866 on a number of children with mental retardation who had a characteristic facial appearance. Not until 1959 did Lejeune demonstrate that Down Syndrome is associated with the presence of an extra chromosome. Since then, other chromosomal rearrangements (some hereditary) resulting in Down Syndrome have been identified, but by far the most common form (trisomy 21) is rarely inherited.

More than 50 signs of Down Syndrome have been identified. Not all signs appear in all cases.

The major characteristics of the syndrome are moderate to severe mental retardation, poor muscle tone, characteristic facial appearance (upward slanting eyes, small round head, small low-bridged nose, protruding tongue), frequent abnormalities of the heart and the eyes, and upper respiratory infections. *

**(Source - Mental Retardation: The Known & Unknown, 1975, Page 21)*

APPENDIX C

POSSIBLE CHARACTERISTICS OF PERSONS WITH MENTAL RETARDATION

1. He/She may be easily led and open to suggestions of others.
2. He/She may be slow of speech and unable to answer questions.
3. He/She may not understand the consequences of what he has done.
4. He/She may be impulsive, or lacking in self-control.
5. He/She may lack motor coordination and may, therefore, make sudden movements that may appear threatening.
6. His/Her movements may be impaired and his slowness may be perceived as sullenness.
7. His/Her reaction time may be slower.
8. His/Her attention span may be shorter.
9. His/Her memory functions are impaired.
10. He/She may not be able to generalize from one situation to another.
11. He/She may not tolerate frustration well and react violently.
12. He/She may not answer rapid fire questions.
13. He/She may be limited in understanding certain concepts and may find it difficult to adjust to what may seem realistic demands of life.
14. Persons with mental retardation need gratification and to feel success and accomplishment the same as anyone else.
15. He/She may have difficulty discriminating right from wrong and need guidance, explanations, patience and understanding to help with specific situations.
16. He/She learns best from real life experiences in small family scale settings.

APPENDIX D

MILESTONES

The Association for Retarded Citizens of the United States has a rich history of improving the lives of people with mental retardation and their families. The ARC also has led the way in research and has educated millions regarding prevention of one-half of the known causes of mental retardation. Leading to ARC's strong leadership role in the field of mental retardation today are the following major historical events and accomplishments:

1950 The first convention of the "National Association of Parents and Friends of Mentally Retarded Children" was held Sept. 28-Oct. 1 at the Radisson Hotel in Minneapolis, Minn.

1952 We became the National Association for Retarded Children and produced a national newspaper, *Children Limited*.

1954 The first National Headquarters opened in New York City. President Dwight Eisenhower declared the first National Retarded Children's Week.

1955 The Association's first film, "Tuesday's Child," was produced. Membership rose to 29,000 with 412 local units.

1956 "Federal Program of Action for America's Retarded Children and Adults" was presented to Congress. Testimony was provided on bills to expand teaching and research in the education of children with mental retardation.

1957 We supported social security coverage for adults disabled in childhood, funding for medical facilities for persons with retardation through the Hill-Burton Act and increased appropriations for vocational rehabilitation programs.

1958 *Mental Subnormality*, an important cornerstone in research literature in the field of mental retardation, reported findings of a three-year Association survey.

Concurrently, support began for research projects and policies formulated for comprehensive programming and institutions.



1959 We published a landmark report, *Decade of Decision*, describing the Association's accomplishments and prospects for meeting service needs of persons with retardation.

1960 *Decade of Decision* was presented to The White House Conference on Children and Youth. Membership totaled 62,000. The Association was approved as one of 10 voluntary health organizations by the President's Committee on Fundraising in the Federal Service.

1961 Under an Association grant, a new screening test for phenylketonuria was discovered by Dr. Robert Guthrie.

1956 to 1961 Federal support for mental retardation services and research increased from \$14 million to \$94 million.

1962 The Association received the Joseph P. Kennedy Foundation International Award.

1963 The President's Panel on Mental Retardation recommended the Mental Retardation Construction Act, maternity and child care projects, expansion of the Vocational Rehabilitation Act and establishment of special education programs.

1964 Membership totaled 100,000. The first interorganization conference on mental retardation convened with representatives from 28 national organizations.

1965 The Association's On-the-Job Training Project was established.

1968 ARC stepped up insistence on immediate eradication of inhumane treatment and improvement of institutional care.

1969 We cosponsored Project Star, a national demonstration of minority and poverty outreach approaches. We initiated the annual holiday card fundraising program.

Also, the ARC opened a Governmental Affairs office in Washington D.C. to increase ARC visibility in our nation's capital and attempt to influence federal policy toward persons with mental retardation and their families.

1970 The National Headquarters was moved from New York to Arlington, Texas, a city more centrally located for the growing membership.

The ARC supported an amendment to the Medicaid program to allow the federal government to begin to finance residential programs and develop standards to upgrade participating institutional programs. This program is known as the "ICF/MR Program."

Early 1970s National and state offices of ARC began to join court suits to defend the rights of citizens with mental retardation living in state institutions and to ensure their right to education. We also became strong advocates of individuals' rights to be served by community-based residential services.

The Association played a major role in the formation of the Developmental Disabilities Services and Facilities Construction Act and spearheaded the formation of the national Consortium for Citizens with Developmental Disabilities. We significantly expanded our involvement with the federal government. This included such diverse issues as immigration, benefits for dependents of service people, early childhood, fair labor standards as applied to workers with mental retardation, lead paint poisoning and immunization programs.

1973 to 1976 We emphasized the complex issues surrounding the use of human subjects in research, both biomedical and behavioral. We made one of the major presentations to the National Commission on Research on Human Subjects.

1974 Reflecting our growing service to adults as well as children, our name was changed to the National Association for Retarded Citizens.

In the mid-1970s, the Association worked for two major programs which significantly impacted on the lives of people with retardation — Supplemental Security Income and Title Twenty Social Services.

1975 The Association's Research and Demonstration Institute was founded. ARC members' hard work securing the right to a public education for all children, regardless of their handicap, was rewarded by passage of Public Law 94-142.

1976 With the International League of Societies for Persons with Mental Handicap, the ARC was host to a "Symposium on Normalization and Integration: Improving the Quality of Life," featuring international experts.

1977 The ARC received two federal grants for the establishment of the federal program information and assistance project. The project trained hundreds of DD advocates in the states about federal programs and developed three comprehensive federal resource guides.

1978 Our activities were directed toward extending and strengthening two acts, Rehabilitation and Developmental Disabilities.

1979 The month of March became Mental Retardation Month, designated by the ARC and The Advertising Council. Also, we addressed the issue of meeting the mental health needs of individuals with retardation and focused attention on legislation to ensure funding for community housing.

1980 "NARC" became the Association for Retarded Citizens of the United States in the most significant name change of our history. State and local units nationwide also adopted a uniform identity by becoming ARC of . . .

1982 The death in Indiana of a baby born with Down's syndrome sparked renewed efforts by ARC toward protecting the lives of other so-called "Baby Does" born with mental retardation and other defects.

Also, in 1982, the innovative Bioengineering Program was launched to utilize technology to meet the needs of persons with disabilities.

At the 1982 National Convention, delegates approved a resolution declaring the right of all persons to community-based services, regardless of the severity of their handicaps.

1984 The ARC spearheaded meetings of national medical and disability groups leading to the signing of the "Principles of Treatment of Disabled Infants" and the passage of the "Baby Doe" Amendments to the Child Abuse Act protecting handicapped newborns from the withdrawal of medical care.

1985 The ARC advocated for persons with mental retardation when the U.S. Supreme Court heard the Cleburne case, in which a group home was denied a permit to exist in Cleburne, Texas. The Court ruled the City of Cleburne's opposition was unconstitutional.

The ARC Bioengineering Program scored its first success when research was completed proving a computer system equipped with voice recognition and environmental control capabilities could be configured for use by people who are profoundly mentally retarded and severely physically impaired.

ARCNET, the Association's electronic mail system, was established. The computer-based system allowed immediate contact between participating local and state ARC chapters. ARC National Headquarters and the Governmental Affairs office in Washington, D.C.

The ARC continued its work toward community integration of people with retardation through support of the Community and Family Living Amendments. The CFLA would direct greater federal funding into family care, small group homes and other community-based services.

The Association also celebrated its 35th anniversary with an open house at National Headquarters in Arlington, Texas.

1986 It was a banner year for key legislative victories with no less than 11 major laws being enacted by Congress and signed by President Reagan. Among that total was the Education of the Handicapped Act Amendments of 1986 (P.L. 99-457). The law mandated a new preschool program for three-to five-year-olds and early intervention services to in-

fants and toddlers from birth through age three.

The ARC also joined with Johnson & Johnson Products, Inc. in conducting a major national awareness campaign highlighting the ARC's work. The campaign was scheduled for March, 1987, Mental Retardation Month.

1987 The ARC/J&J awareness campaign reached an estimated 75 million households through newspaper coupon inserts and a full-page ad in *Reader's Digest* promoting the effort. Johnson & Johnson, pleased with the campaign's success, announced plans to work with the Association to repeat the awareness campaign in March 1988.

An important Supreme Court ruling in "*School Board of Nassau County, Florida, v. Gene A. Arline*," extended protections of Section 504 of the Rehabilitation Act of 1973 to people with contagious diseases. The ARC filed a friend of court brief in the case concerning the possible impact the court's decision might have on people with retardation who also have hepatitis.

In an effort to ensure the availability of community health care for people who are mentally retarded, the ARC joined in a collaborative effort with several other organizations to form the National Consortium of Community Health Services for Persons with Developmental Disabilities.

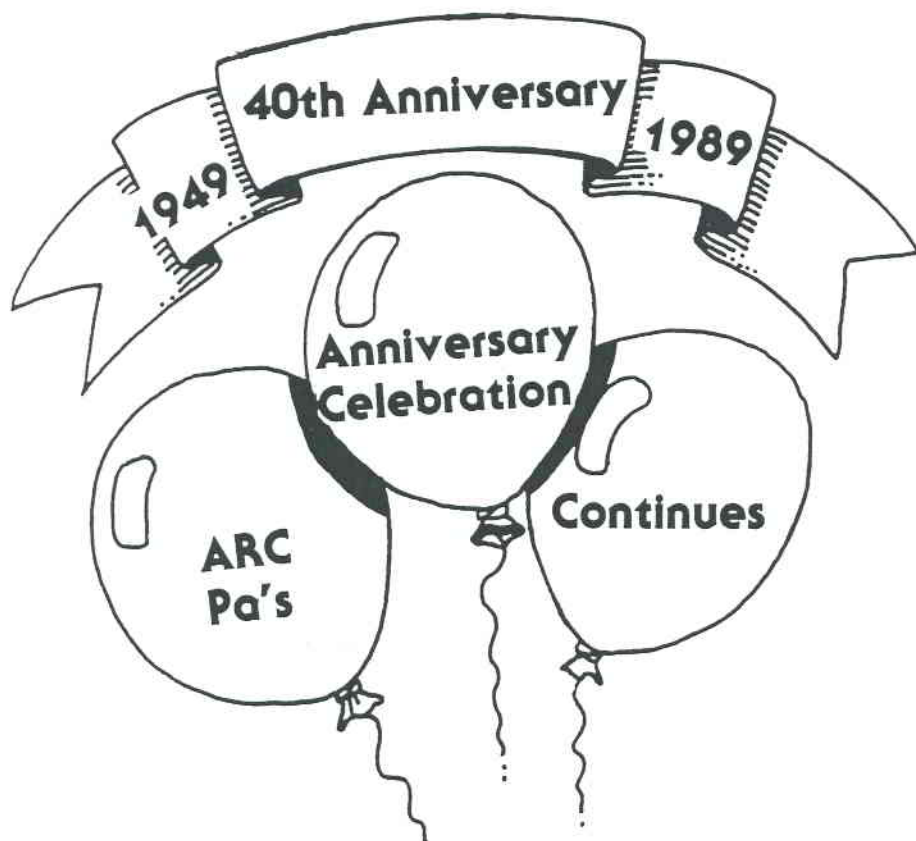
Also, the ARC's On-the-Job Training Project changed its name to National Employment and Training Program in order to reflect its greatly expanded scope. By 1987 the NET Program encompassed such activities as supported employment, professional and volunteer training, job development and placement and more.



arc

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The Association for Retarded Citizens, Pennsylvania continues to recognize its 40th Anniversary throughout 1989. Reviewing the organization's purpose and relating these goals to the newsletter headlines over the past years provides insight into our accomplishments. ARC strives to promote the general welfare of persons with mental retardation; monitors all services to assure our citizens are receiving high quality programs which meet their needs; develops appropriate public awareness measures to educate and inform; encourages the formation of county chapters to provide services at the local level; collects and disseminates information on a variety of pertinent issues; and encourages the development of integrated programs. "Pennsylvania Message" headlines dating from 1965 indicate over two decades of ARC dedication to serving Pennsylvania's citizens who are mentally retarded. They are as follows:



1965 - PKU Bill Passes House.
1966 - MH/MR Act of 1966 Passes Both Houses of Legislature
1967 - Experimental Play Highly Successful
1968 - Hearings on MH/MR Regulations; New Residential Facility for Southeast Area to Feature Small Groups, Community Relations; and Progress in the Prevention of Mental Retardation
1969 - Aroused Public Calls for Pennhurst Reforms; Deficiencies in other Institutions Cited; PARC Delegates Adopt Bill of Rights; and Institution Appropriation at Least \$10 Million Short!
1970 - PARC Asks Probe Of Residential Facilities

1971 - Parents to be Heard Before Child Excluded; Death Knell May Sound On M.R. Institutions; and PARC Files "Right To Education" Suit
1972 - Retarded Guaranteed Right to Education; Court Order Signed. . . Childhunt Begun; Developmentally Retarded Children Can Learn in Infancy and Early Childhood!; and "It's Been a Long Time Coming" -- The Separation of Mental Health and Mental Retardation
1973 - Pennsylvania Fellowship Plan Updated: Citizen Advocacy; and Welfare Secretary Bans Cages or Pens In All Institutions
1974 - Design for Living - The PARC Plan Completed; De-

Institutionalization: Convention's Key Issue; and Peonage Ends in Court Order

1975 - Education for the Handicapped Bill Passes Senate; and DPW Announces Medical Assessment Program

1976 - Court Commitment Statute Declared Unconstitutional; County Commissioners Named In Pennhurst Suit by PARC

1977 - Philadelphia ARC Reopens Right to Education Suit; and Halderman v. Pennhurst Finally In Court

1978 - Pennhurst Residents To Be Placed In Community

1979 - Polk Center Undergoes Scrutiny; and Group Home Residents Eligible for Food Stamps

1980 - Supreme Court Hears Pennhurst Case

1981 - Supreme Court Rules On Pennhurst Case; and Federal Budget Cuts Threaten MR Programs

1982 - Federal Educational Department Threatens Quality of Education; and Commonwealth Appeals Pennhurst Decision to the Supreme Court -AGAIN!

1983 - Pennhurst Will Close; Handicapped Newborns Protected by Federal Rule

1984 - "Pennhurst Settlement Threatened" Waivers Turned Down by Feds; and The Supreme Court will Hear Cleburn, TX v. Cleburn Living Center.

1985 - New Community Service Bill S.873 -- "The Community and Family Living Amendments of 1985"

APPENDIX E

LOCAL ARC CHAPTERS

Allegheny County
1001 Brighton Road
Pittsburgh, PA 15233
412/322-6008

Berks County
512 Penn Avenue
West Reading, PA 19611
215/374-4200

Cambria County
960 Bedford Street
Johnstown, PA 15902
814/535-1511

Chester County
24 South New Street
West Chester, PA 19382
215/436-6740

Dauphin County
4401 Linglestown Road
Harrisburg, PA 17112
717/540-5800

Franklin/Fulton Co.
554 Chambersburg Trust Co.
Chambersburg, PA 17201
717/264-4390

Lackawanna County
115 Meadow Avenue
Scranton, PA 18505
717/346-4010

Lehigh/Northampton Co.
1036 North Godfrey Street
Allentown, PA 18103
215/434-8076

Mercer County
P.O. Box 1069
850 Hermitage Road
Hermitage, PA 16148
412/981-2950

Armstrong County
405 Ninth Street
Ford City, PA 16226
412/763-9116

Blair County
1219 14th Avenue
Altoona, PA 16601
814/946-1011

Carbon County
178 S. First Street
Lehighton, PA 18235
215/377-6671

Crawford County
884-886 Market Street
Meadville, PA 16335
814/724-7346

Delaware County
111 North Lansdowne Avenue
Lansdowne, PA 19050
215/622-2220

Greene County
P.O. Box 431
Waynesburg, PA 15370
412/627-5511

Lancaster County
630 Janet Avenue
Lancaster, PA 17601
717/394-5251

Luzerne County
53 N. Main Street
Suite 200
Wilkes-Barre, PA 18701
717/829-7953

Montgomery County
Valley Forge Plaza
1150 First Avenue
King of Prussia, PA 19406
215/265-4700

Beaver County
Beaver Valley Prof. Bldg.
Suite #103
1260 N. Broadhead Road
Monaca, PA 15061
412/775-1602

Butler County
100 N. Washington Street
Butler, PA 16001
412/282-1500

Centre County
305 South Burrowes Street
State College, PA 16801
814/238-1444

Cumberland/Perry Counties
P.O. Box 386
117 N. Hanover Street
Carlisle, PA 17013
717/249-2611; 697-8343

Erie County
1140 E. Lake Road
Erie, PA 16507
814/452-4865

Indiana County
720 Church Street
Indiana, PA 15701
412/349-8230

Lawrence County
101 South Mercer Street
207 Central Building
New Castle, PA 16101
412/658-8515

Lycoming County
445 1/2 Grant Street
Williamsport, PA 17701
717/326-6997

Northumberland County
2nd. & Walnut Streets
Shamokin, PA 17872
717/648-2871

Philadelphia County
2350 W. Westmoreland Street
Philadelphia, PA 19140
215/229-4550

Union/Snyder Counties
P.O. Box 465
Lewisburg, PA 17837
717/523-1117

Venango County
P.O. Box 421
Oil City, PA 16301
814/676-8406

Warren/Forest Counties
P.O. Box 244
Warren, PA 16365
814/723-8531

Washington County
P.O. Box 385
Meadowlands, PA 15347
412/222-6960

Westmoreland County
15 West Third Street
Greensburg, PA 15601
412/837-8159

Wyoming County
68 E. Tioga Street
Tunkhannock, PA 18657
717/836-4001

York County
240 E. Haymeadow Drive
York, PA 17402
717/846-6589

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