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A Vision Unfolding: The Al Sigl Center's First 25 Years, 1968 - 1993

by Kathy A. Johncox



Cover: Alphonse J. Sigl (1883-1966) was the good neighbor whose spirit lives on at the Center which bears his name.

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A Vision Unfolding: The Al Sigl Center's First 25 Years, 1968 - 1993

The story of the Al Sigl Center began in March 1955 when Dr. Ira Hiscock, Chairman of the Department of Public Health at Yale University, completed a study for the Council of Social Agencies. His report, A Study of Public Health in Rochester and Monroe County, New York, was a portrait of a socially-conscious and forward-looking post war community. It recommended "creating a single, large community rehabilitation center with as many as possible of the existing rehabilitation services in the community included...with the idea that they would begin to use common services and integrate their program efforts."

Advocacy and quiet agitation for expanded and better coordinated social services had been growing in the community for some time. The Hiscock Report gave these sentiments expression and focus. A year later, in March 1956, a committee chaired by Kodak executive Hiram G. Hanson was appointed to implement the recommendations.

Several points in the Hiscock Report guided the new committee in its mission. There was uncertainty about whether all of the health needs of the public were being met. The public was vague about health care services provided in Monroe County. There was resistance to cooperation and a fear of loss of autonomy, a concern that continued throughout more than a decade of planning for the center. Hiscock further recommended that the guidance and research consultation available through the University of Rochester, Strong Memorial Hospital and the School of Dentistry be utilized.

In November of 1960, Dr. Donald Anderson, Dean of the University of Rochester School of Medicine, and Irving Briggs, a Board Member of the United Cerebral Palsy Association, proposed the development of a handicapped children's health center where services could be better coordinated, duplication of effort could be eliminated, and economies could be maximized.

In March of 1962 the Monroe County Center for Rehabilitation Agencies (MCCRA) was incorporated with seven member agencies: the Association for Retarded Children, Inc., the Day Care Training Center for Handicapped Children of Monroe County, Inc. (now the Mary Cariola Children's Center), Medical Motor Service of Rochester and Monroe County, Inc., Rochester Area Multiple Sclerosis, Inc., Rochester Rehabilitation Center, Inc., Hearing and Speech Center of Rochester, Inc. (now the Rochester Hearing and Speech Center), and the United Cerebral Palsy Association of the Rochester Area, Inc.

Several other agencies had considered membership in the proposed center. Many had resources or substantial property which they were reluctant to share. The seven founding agencies had little or no resources. What they did have was the passion of family and friends who knew the special needs of the people they served.

A combination of serendipitous events led to the incorporation of these agencies. First, Justin Vigdor, President of the MCCRA Board, observed that some of the agencies needed services that the others provided. At the same time the Community Chest was encouraging the sharing of community resources and discouraging duplication of agency services. Secondly, the state had closed a portion of the State Hospital on the northeast corner of Elmwood and South Avenues making available land for construction of the new center near to the University of Rochester's medical complex. Thirdly, MCCRA learned that the center qualified for the federal Hill-Burton Program that provided capital for construction of health facilities. The committee decided to move ahead with plans for construction of the center immediately.

With no permanent homes, the agencies moved frequently, often into inadequate space, and struggled to meet basic program needs. In May 1962, Kodak industrial engineers volunteered to survey and quantify the space needs and dreams of the agencies for the first time. Their report created the first picture of separate areas for each agency with common space where shared purposes overlapped.

In February 1964 John W. Briggs was hired as architect, and the 10 acre state hospital site was purchased for \$32,500.

The idea that public buildings should be designed for handicapped accessibility was a radical one in the 1960s, already a period of social change and a time when people felt they could make a difference in community welfare. The concept of a single center built to serve the needs of several related agencies began to change the attitudes of people towards handicapping conditions.



At the dedication of the Al Sigl Center for Rehabilitation Agencies, New York Secretary of State John P. Lomenzo gave the address. He congratulated the Rochester community for its generosity. (left) Miss Kathy Melnick, a secretary, and Al Sigl sculpture by Achille Forgione.

Briggs set about designing a model barrier free building with room to grow. Nothing would be casual about the new center. It was purposely located in the heart of Rochester's health service district. It would be an attractive campus on a bus line on a visible corner to symbolize that people with disabilities are fully a part of community life. Of the \$4 million needed for the building, the sale of the agency properties and reserve funds contributed \$300,000. State and federal grants totaled \$1.5 million. The balance, over \$2 million, needed to be raised from the community.

A substantial state grant required that construction begin by June 30, 1966. The new board did not want to take a chance on funds being available again the following year. In spite of some concern expressed by the Community Chest, the board proceeded with construction. Several of the founding agencies now were desperate for new facilities, because they had avoided maintenance and capital expenditures in anticipation of a new center. The board gambled on community trust and the dedication of 2,000 campaign volunteers and won. The media supported the capital campaign in 1967 and, though the initial campaign fell short of its goal, a balance of need effort raised the money needed to complete the center.

During construction, the board searched for an appropriate name for the new center. In 1966, Al Sigl, a popular radio personality on WHEC, died. When the building campaign was announced, a pastor donated the church's Al Sigl Memorial funds to it. Sigl was noted for his charity. At noon every weekday throughout the 1930s, 40s and 50s, he opened his broadcast with a gravelly greeting, "Howdy neighbors!"; a greeting the community associated with neighborliness and community giving. Sigl would broadcast the need for furniture for burned-out families, or for donations of crutches or wheel chairs.

Sigl attracted nationwide attention when he gathered and listed the blood types of 600 potential donors in what became the nation's first civilian blood bank. Whatever the community need, his broadcasts brought an outpouring of donations and offers of help. It was this image of community concern and public service that brought the committee to name the center after Al Sigl.

After more than a decade of work by families and friends of people with disabilities and people who stepped forward to take leadership, the Al Sigl Center opened at 1000 Elmwood Avenue in February of 1968. The Al Sigl Center offered the member agencies and their 3,400 clients individual space and the added value of shared space which no one agency could afford or justify: a campus setting, accessible parking, a full-size therapeutic pool, a gymnasium and locker rooms large enough to accommodate large numbers of people in wheelchairs, cafeteria, lounges, conference rooms, and outdoor play areas adapted for children with special needs.

By May 18, 1969, when the new Center was formally dedicated, it was already clear that membership in the Center made the agencies stronger and better recognized than when they were on their own. It was also clear that the hard work and planning paid off - the new environment worked beautifully.

James Moloney, who had been construction manager, stayed on as the Center's first and, for a short time, only staff member. As building manager and Administrator, it was his job to relieve the agency executive directors of all building-related matters, a job he performed admirably for 22 years.

Elasticity seemed to have been a key ingredient in the Center's construction. Space was frequently rearranged to accommodate growth. When there was no more stretch, the Center expanded. In the 1970s, it added a six-bay bus garage and acquired 5 acres on South Avenue from the County. In 1980, a \$3.5 million wing was added for the Mary Cariola Children's Center and the Medical Motor Service,

freeing space for other agencies. Fundraising was difficult for this building project and required another balance of need campaign.

In 1986, the Epilepsy Association of Greater Rochester (EAGR) joined the Center as the first new member agency and needed Al Sigl Center space. Increasing numbers of children and adults with disabilities were requiring services from the Mary Cariola Children's Center (MCCC) and the United Cerebral Palsy Association(UCPA). Both agencies had leased classroom space in surplus suburban schools. School districts needed the space back to accommodate growth in school-age populations. New construction was a priority.

In 1987, anticipating a major capital campaign, the Center began construction of a second wing of twelve classrooms for MCCC at the Elmwood Campus and an addition to the Association for Retarded Citizens' greenhouse, originally built in 1975, at the Elmwood Campus. The next year, construction began for the Winton Campus on 9 acres at the corner of Winton and Castle Roads in the Town of Henrietta to house UCPA and EAGR. A \$6 million campaign was kicked off in October of 1988 with a new level of community involvement under the leadership of Alan Hasselwander, President of Rochester Telephone Corporation.

Winton Campus opened in February, 1990 and was dedicated on May 4, 1990 as the Hale Building to honor the leadership gift from Pat and Bill Hale. The capital campaign ended in 1991 with \$7.1 million. Community support of the Center was now well-established, and a new Board of Governors was charged by the Board of Trustees to oversee ongoing resource development.



Dedication of the Hale Building at the Al Sigl Center Winton Campus honored many members of the community, particularly the Hale family for their leadership gift which made the new campus a reality. Mrs. William B. Hale II and Mrs. James L. Hale receive a special thank you from Rachel Werner, a client of the Epilepsy Association of Greater Rochester, and Daniel M. Meyers, Al Sigl Center president.

The Medical Motor Service of Rochester and Monroe County, Inc: Specialized Transportation

What is now the Medical Motor Service of Rochester and Monroe County, Inc. (MMS) began in response to an influenza epidemic in the winter of 1919. A year earlier, a group called the Junior Health Workers had organized to transport nurses of the newly formed Public Health Nursing Association(PHNA)to homes and patients to clinics. Over the next few years, demand for volunteer transportation services increased. All over the country women had been volunteering as drivers for the Red Cross during World War I and the influenza epidemic of 1919. Another influenza epidemic in 1925 may have brought the need for this transportation service to the attention of Rochester's leading women. Discussions at tea parties and social events were catalysts for raising the awareness of Rochester's most influential women to attend to the needs of the community's less fortunate.

The need for medical transportation overwhelmed the Junior Health Workers and became so great that the Women's Volunteer Motor Service was organized in May of 1925 by the Women's Council of the Federation of Churches, the Catholic Women's Club and the Council of Jewish Women.

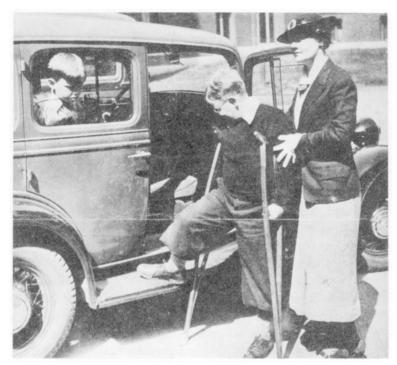
Margaret Ellwanger supplied a new Star touring car. Appeals for volunteer drivers ended by asking for people to lend automobiles and either drive themselves or lend their chauffeurs.

During the following few years with no public funding, the survival of the Women's Volunteer Motor Service depended upon donations. The Chatterbox Club donated a new car in 1927 and the Rochester Female Charitable Society started paying the up-keep of the car and the driver's salary.

In 1931 the Women's Volunteer Motor Service became supported by the Rochester Female Charitable Society and membership dues. The Service had a board of 27 directors, all women. A constitution was adopted and president Mary M. Townson was elected. The Society maintained the Motor Service car and paid the driver.

Reports of the work of the Volunteer Motor Service were often featured on the society pages of the local newspapers. In the first year this independent agency made 780 trips, the second year 1624. In 1937, 2,123 hours were donated by volunteers and 2,612 trips were made by the Motor Service automobile.

The outbreak of World War II changed the nature of the



A newspaper clipping from the Democrat and Chronicle, May 17, 1936 shows driver, Mrs. Herbert Ward helping two young clients on one of the 2,572 free trips to local clinics made that year by the Women's Volunteer Motor Service, now the Medical Motor Service.

organization as it placed "personnel and resources of the organization under the direction of the local Red Cross during emergencies." As the war progressed gas became scarce and only the hired driver, Mrs. Phillip O. Viall, continued to take patients to the hospitals. Volunteers who transported social workers and nurses were forced to stop activities "for the duration".

After the war, then president of the board of directors, Dorothy M. Swan, requested that the Council of Social Agencies make a study and a major evaluation of the service to the community. Results indicated that hospitals considered the transportation of patients to hospitals "essential and indispensable" but that transportation of workers need not be re-established. The committee also recommended a name change since drivers were no longer volunteers. The agency reincorporated in 1946 and the name was changed to the Medical

Motor Service of Rochester and Monroe County, Inc.(MMS). The agency became a participant in the Community Chest.

By the mid 1950s, four cars, all driven by women, were in operation, and volunteers, although they no longer drove the cars, continued to be a driving force in the agency performing vital day to day functions that helped to guarantee the organization's success.

In 1961, a committee was formed under the Health Division of the Council of Social Agencies to investigate transportation problems in the community. A sub-committee of people in the transportation field was formed and led by Francis P. Ryan of Eastman Kodak. In 1965, his appointment to the Medical Motor Service board broke the tradition of all female trustees.

Up until 1966, the agency had operated with a part-time, then a full time secretary. As the agency expanded, the work became more complex and in 1966 Barbara Stephens became the agency's first Executive Director.

On Feb. 19, 1968, MMS became one of the seven agencies that moved into the new Al Sigl Center. Two of the agencies, the Day Care Training Center and the United Cerebral Palsy Association, each owned two wagons and had provided transportation for children in the city. These vehicles and drivers were transferred to MMS in 1969.

In 1976, MMS only provided medical appointment transportation, but with the addition of a chairmobile owned by Monroe County, chairmobile service was resumed and service was extended for social, recreational, and personal reasons not covered by Medicaid.

In 1978 the Monroe County Office for the Aging consolidated senior center transportation under MMS and six centers were served. In 1983, MMS began to provide services to the Association for Retarded Citizens for clients entering their day treatment program. From 1983 on, the agency began to take an aggressive role in coordinating and providing a variety of transportation services for other agencies.

Passage of the Americans with Disabilities Act in 1992 increased the number of facilities accessible to people with disabilities and required a close working relationship with Rochester-Genesee Transit Authority with the goal of maximizing the collective resources in transportation for the community.

In 1992, MMS moved into renovated 19th century stables left over from the old County Penitentiary on South Avenue next to the Al Sigl Center's Elmwood Campus. Maintenance staff at the Al Sigl Center did most of the renovation work, providing much needed space for the growing number of staff necessary to continue high quality transportation programs in the 1990s.

In 1991-92, seventy-five vehicles traveled a total of 272,669 trips were provided to over 4,500 Monroe County residents with disabilities or mobility problems. Seventy-five vehicles traveled almost 1.5 million miles.

The spirit of the early volunteers lives on in the Medical Motor Service where dispatchers considerately arrange and drivers compassionately provide specialized transportation for clderly people and for children and adults who are ill or disabled.

The Rochester Rehabilitation Center: Retraining for the Workplace

"Isn't it true that the greatest fear of any convalescent today is not only how soon he can again take up his regular occupation, but if he will ever be able to do so and how?" Reflections of a patient (anonymous) who was treated at "Little House" 1922.

The Rochester Rehabilitation Center (Rehab Center) has roots in the aftermath of an outbreak of tuberculosis in 1919. At that time the Rochester Tuberculosis and Health Association began a six month demonstration project designed to study the value of occupational therapy to the many patients with tuberculosis at Iola Sanitarium. When that project ended, Elizabeth Wise, an occupational therapist, was employed to visit these patients in their homes. Realizing that home services from only one occupational therapist were inadequate, Miss Wise, several physicians and some interested members of the community, approached the Women's Industrial and Educational Union and received \$800 to buy equipment and rent space for an occupational therapy center. Miss Wise became director of the occupational therapy workshop "Little House" at 160 Chestnut Street in January of 1922.

In 1924, "Little House" moved to larger quarters at Washington Street and became the Curative Workshop. In 1926, the Workshop moved to Wisner Building at 75 State St. and added an industrial therapy division, a workshop that offered activities that would lead individuals back to the type of work done previously or prepare them for something new. The agency also began to consider expanding services to give permanent part time employment to persons with heart disease, arthritis, traumatic injuries and other diseases.



In the Rochester Rehabilitation Center's wood shop at the Sibley building on Prince Street, people with arthritis, heart disease, traumatic injury or other disabilities that affected their ability to work, learned to use jigsaws and other woodworking equipment. After retraining, they were offered part-time employment at the Rochester Rehabilitation Center's workshop.

In 1932, the agency joined the Community Chest, separated completely from the Tuberculosis and Health Association, and incorporated as the Industrial Workshop. The agency continued to grow, moving several more times before buying property at 233 Alexander Street.

In 1945 the Industrial Workshop became the Rochester Rehabilitation Center with physical, occupational, and industrial therapy departments. By 1955, 50% of referrals to the industrial division were from the Office of Vocational Rehabilitation (OVR) and the agency solved its need for more space by buying the Sibley Library Building on Prince Street.

In the 1960s, the agency's role emerged as one of assisting people with disabilities to achieve maximum independence in physical, economic and social arenas. By 1966, most types of disabling conditions were represented in the agency's caseload. The agency became more involved with people with severe mental and physical disabilities and habitual alcoholics from the Monroe County Penitentiary. In 1967, under the leadership of Earl Fahy, executive director, a 100% increase in funding from a Monroe County Board of Mental Health contract resulted in major expansion of staff and programs. Driver education and training, homemaker rehabilitation, wood-working, cardiac work evaluation programs and a dental lab were developed. In 1968, the Rochester Rehabilitation Center moved into the largest agency suite of space in the Al Sigl Center.

In 1975, a United Community Chest Task Force recommended expansion of the sheltered workshop. Over the next ten years, the agency developed workshop sites on Clinton, University, and Mt. Hope Avenues. In 1977, the Rehab Center served over 1,000 clients; by 1983, it served nearly 2,200.

Through the 1970s, although referrals for services from OVR declined, physical therapy and driver education programs grew with the help of individual payment and reimbursement from insurance companies.

In the 1980s, budget cuts significantly reduced state mental health funding contracts and the agency developed a strategy to increase referral and funding sources. The Rehab Center increased government and business connections when it won a contract with the Government Services Administration for custodial maintenance services at the Federal Building. The contract provided 16 full-time equivalent jobs for disabled workers opening the door from traditional sheltered workshop environments to true community-based employment.

In 1986 the Rehab Center received approval as the only Comprehensive Outpatient Rehabilitation Facility (CORF) in upstate New York. In that same year, the Rehab Center began work with substance abuse and opened two supported employment programs: one for chronically mentally ill people and one for individuals with head injuries. Grants enabled the center to offer outreach services for elderly mentally ill homebound people and people with physical disabilities. When the Rehab Center needed more space for these initiatives, the Al Sigl Center converted 12,000 square feet of former workshop space to allow for the expansion. The agency moved the workshop into the community where low cost light industrial space

was available.

In 1989, an expanded CORF celebrated its grand opening in the newly renovated space at the Al Sigl Center. It included its own therapy pool and kitchen, bedroom and living areas where people with traumatic brain injury and other types of disabilities could participate in rehabilitation therapies.

In 1990, the Out-Source, the workshop on University Avenue secured nearly one million dollars in manufacturing business and an additional one-half million in service contracts resulting in the hiring of 220 workers and trainees with severe disabilities. One of the program's contracts was with Eastman Kodak to recycle disposable cameras.

In response to the Americans with Disabilities Act, in 1992 the Rehab Center provided accessibility surveys and training programs for managers and supervisors in area businesses.

The Rehab Center provides an array of services to over 4,000 people with disabilities: a comprehensive multi-disciplinary outpatient rehabilitation program, a community reintegration program for people with head injury, independent living services, driver rehabilitation, mental health outreach programs and participation in the New York State Drug and Alcohol Education Program.

The Rehab Center's commitment remains to reach out with comprehensive community-based services that will help people regain physical, social, emotional, and vocational independence.

The Rochester Hearing and Speech Center: Early Intervention

On May 22, 1922 Alice Howe Hatton, a lip-reading teacher in the Rochester public schools, called to order the first meeting of the League for the Hard of Hearing at the Women's City Club. The League was concerned with social issues of people with hearing problems and the organization's purpose was to provide educational, recreational and vocational assistance to hearing impaired adults and children. Many of the organizers were teachers who taught lip-reading in the Rochester school system and other volunteers concerned with the "prevention of deafness" especially in children. To encourage early intervention, Dr. Franklin Bock, a local physician and a director of the League, regularly conducted free hearing examinations for children in the city schools.

The following year, the League rented offices at 91 Monroe Avenue. Lip-reading practice classes were organized and held there by volunteer teachers of the deaf. Dr. Bock was still conducting the screening program and in 1926 reported there were 300 children with hearing impairments in the city schools. Increased screening efforts tested 1500 children in three days at Madison Junior High School.

In 1928 the League was incorporated as the Rochester League for the Hard of Hearing and the following year, became a member of the American Hearing Society. Hearing aid demonstrations and vocational guidance were available for those seeking employment. A transportation fund was established to enable children from Charlotte to attend lip-reading classes and Christmas baskets were sent to needy hard-of-hearing people.

From the late 1930s to the early 1940s it was impossible to raise enough money to carry out the League's programs. A request was drafted to the Council of Social Agencies for membership. With this idea, the League took the first step to evolution from a purely a social agency to a social service agency and in 1943 received acceptance as a Red Feather Agency.



Hearing and Speech Center of Rochester (now Rochester Hearing and Speech Center) facilities at the Al Sigl Center included four fully-equipped sound suites with observation windows for audiologists to use when testing hearing in children and adults.

After World War II, the Council for the Study of Post-War Problems in Rochester recommended that an agency be developed to treat both speech and hearing problems of returning veterans as well as area residents. In 1952, the Board of Directors of what was by now called the Rochester Hearing Society voted to expand services to those with speech problems as well and they changed the agency name to the Rochester Hearing and Speech Society. For the first time funds were requested from the Community Chest for program expansion, and the request was approved. The agency bought its first audiometer to use for hearing testing, devised a better system of records, and formed a stronger advisory committee which included some of the most prominent people in the Rochester area.

In 1956, while the agency was located in offices at Rochester General Hospital on Washington Street, the name was changed to the Hearing and Speech Center of Rochester (HSCR). The agency employed one speech pathologist and one audiologist. While at this location, well before construction of the building that would bear his name had begun, the speech pathologist provided speech therapy for Al Sigl himself after a laryngectomy left him unable to speak and in need of speech retraining.

In 1968, after temporary quarters at 907 Culver Road, HSCR settled into the new Al Sigl Center. This new space offered observation rooms and custom designed testing suites made specifically for the agency's needs.

In 1969 the agency developed strong community outreach and early intervention programs for diagnosis and treatment of speech and hearing problems for both children and adults. The Center acquired a mobile hearing testing van that traveled to industries, day care centers and migrant child care facilities. Satellite centers were opened in day care centers and other places in high need areas to serve people closer to their homes.

In 1970, HSCR began the Preschool Group Language Program that substituted the traditional one-on-one speech therapy for preschoolers with therapy provided to small groups of children. They received intense language training by a single speech-language pathologist while parents observed and later met to discuss behavior and other concerns.

The Center continued to add staff and develop innovative programs and by the mid 1970s was one of the largest independent hearing and speech facilities in the northeastern United States. With the acquisition of special hearing testing equipment, the Center established the county-wide High Risk Register/Infant Hearing Alert Program with area hospitals in 1975. The Center provided hearing tests and hearing aid recommendations for infants as young as 6 months.

With John Paris as Executive Director, the Center continued to develop joint programs and expand client services. In 1986, the first ECCELS (Early Childhood Class for Expressive Language and Speech) classroom opened in response to requests by parents of children who had been enrolled in the Group Language Program. Some parents wanted HSCR to offer a choice of 3 or 5 day programs with unrestricted parent observation, weekly parent education groups and parent training in the language needs of their children. The degree of parent involvement was unique for this type of program in the Rochester community. In 1992, ECCELS expanded to three classrooms.

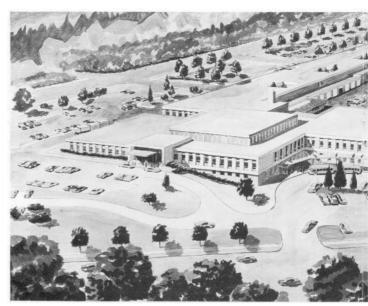
The early 1990s saw the development of an annual equipment fund appeal to help the Center replace and acquire state-of-the-art hearing testing equipment. A partnership with Rochester Telephone Corporation led to the Telephone Evaluation and Demonstration Center, a free clinic where people could come to try different kinds of amplified telephones. Another free clinic, the Assistive Device Demonstration Program, offered people the opportunity to try devices that might help improve hearing in certain situations.

In early 1993, the agency assumed the business name of Rochester Hearing and Speech Center to emphasize its years of leadership in providing help for children and adults in Rochester and surrounding areas. The agency continues to focus on providing early intervention for children and adults with hearing and speech problems, and on involving their families in the treatment.

What began as an effort to serve several hundred school children has grown to serve over 6,000 children and adults annually at the Elmwood campus and another 8,000 in community settings.

United Cerebral Palsy Association: Independence in spite of Physical Challenges

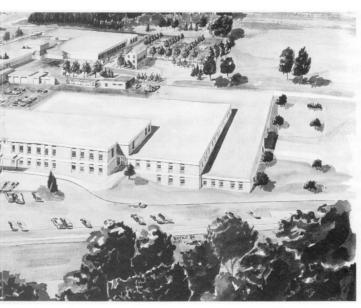
On one of his radio broadcasts in 1945, Al Sigl made the following announcement: "Ladies and Gentlemen, I have a most amazing letter here from a Mrs. Larry Andrews of Seneca Falls. She says she would like to give away a walker that was custom built for her daughter who has cerebral palsy. The fascinating thing about this is that she says there are over 10,000 of these cases in New York State. Ladies and Gentlemen...I have never heard of cerebral palsy."



Since the Al Sigl Center opened in 1968, two new wings have been added to expand space for the Mary Cariola Children's Center and the Medical Motor



The Hale Building, Winton Campus opened in 1990, housing a mucl consolidate children's and adults' programs at one location, and providing



to the Elmwood Campus on South Avenue, one in 1980 and one in 1987 to or Service. These expansions also provided additional space for other agencies.



ch needed expansion allowing the United Cerebral Palsy Association to ng a home for the Epilepsy Association of Greater Rochester.

Awareness of cerebral palsy locally spread quickly after that. Soon Al Sigl made another of his many appeals for help, this time for a tricycle that could be used for a physically handicapped child. Mrs. Ralph Amdursky, mother of a handicapped boy, heard the appeal and discussed it with her husband. Discouraged by the lack of services for their son, they decided to try to get in touch with other parents of handicapped children to form an organization. They asked Al Sigl to announce over the radio that such a group was being formed. He agreed and also asked for listeners to give him the names of anyone who had a physically handicapped child or anyone with a physical disability. Seventy parents were invited to the first meeting at the home of Mr. and Mrs. William Woodworth. Al Sigl himself spoke about the latest development in his drive to help the "spastics".

The group met again at the Rochester Public Library in January 1946 and elected its first officers and directors. In April, the group had moved to establish a cerebral palsy center to provide treatment for children and support for their families. They had sent a representative to the New York State Cerebral Palsy meeting.

Temporary headquarters were established in a store at Chestnut and George Streets. The organization desperately needed money. Start up funds came from an Easter Seals campaign. The fledgling group began to look for a facility, and found a mansion at 1570 East Avenue for sale at the cost of about \$5,000. One of the first contributions from outside the parents' organization was \$6,000 from the Elk's Club, the results of one card party staged for the benefit of the association. Other community groups became interested and began some fundraising projects for the group. One of these women's groups took the name of Chapter One of the Cerebral Palsy Association.

Before these parents came together, they did not have much choice about what to do for their children. Often institutionalization or 24 hour home care were their only options. Parents were on their own to try to find ways to keep families together and help their handicapped children. It was the parents' group that became the United Cerebral Palsy Association of the Rochester Area, Inc. (UCPA) on November 18, 1946.

Staff consisted of an occupational therapist, a secretary, a medical social worker, four aides, a housekeeper, a cook and a maid. Meetings were so well attended that they had to be held at the nearby Academy of Medicine to accommodate everyone.

In 1947, the association voted to become a Red Feather Agency with the needed support of the Community Chest. That year also the Edith



As early as 1949, volunteer engineers from local industries worked with occupational therapists at the United Cerebral Palsy Association to design specialized equipment to enable children with cerebral palsy to move independently.

Hartwell Clinic, an in-patient treatment center for children with neuromuscular difficulties, opened in LeRoy, was financed through the National Foundation of Infantile Paralysis and staffed by medical specialists and orthopedists from Strong Memorial Hospital. The clinic later was relocated to the hospital's rehabilitation wing.

In 1948, the Chapter One group suggested that since children were coming and waiting for their therapies anyway, a nursery school room might be a good place for the children to wait. A nursery school teacher from Canada, Winifred Fletcher, was hired to open the nursery school. She became executive director in 1951.

Education was a concern for parents whose children were long past the age at which most children entered school. The Center hired its first certified elementary school teacher and budgeted for this position until the mid 1950s when Board members persuaded the Board of Education to supply the teacher and necessary supplies. As the children became young adults, UCPA debated renovating a carriage house on the property to improve recreational facilities, but ultimately decided to build a new structure. A local contractor, approached by a committee of mothers, agreed to build it for less than half the cost.

In the early 1960s, board member Irving Briggs saw to it that UCPA took a lead role in developing the concept of the Al Sigl Center. Briggs recognized that each agency wanted to retain its autonomy, identity and focus. The idea of retaining agency independence and removing the constant concerns about adequate space was appealing. UCPA was one of the founding tenants when the Center opened in 1968.

The number of families seeking help grew as community awareness of the Al Sigl Center concept and its member agencies grew. By the time UCPA moved into the Al Sigl Center, they already needed more space. The agency rented a school building in Irondequoit for children and one in Brighton for adults to house programs until they could increase Al Sigl Center space.

Children and adults with cerebral palsy and other physical disabilities were transported to program by the Medical Motor Service, received speech therapy and audiology services from the Hearing and Speech Center of Rochester, shared physical therapists with the Mary Cariola Children's Center and used the Rochester Rehabilitation Center for rehabilitation evaluations for adults.

Outreach programs offered home services to parents and families and evaluation and social work services were also offered to families in other counties and rural areas under the New York State Elk's Project. Discovery Day Care opened in 1983 as the only integrated day care center in the community where children with and without disabilities played together.

In 1990, UCPA moved into the Al Sigl Center Winton Campus, a fully handicapped accessible, spacious facility adapted to the special needs of those they served. It was a dream come true for the 100 children and 170 adults who participated in the day treatment programs. By establishing unique, innovative treatment and support, UCPA has made the community aware of and opened opportunities for physically challenged children and adults and their families.

Rochester Area Multiple Sclerosis: Socialization and Accessibility

In 1948, Howard Benjamin was a Monroe County Infirmary patient with multiple sclerosis (MS), a disease of the central nervous system. Benjamin conceived of an association for people with MS in order to improve their social life and to try to make buildings and public places accessible to people with physical disabilities. He called his friend, Al Sigl to make a radio appeal for names of people with MS and their families. Response to the broadcast was excellent. Groups met informally for several years until 1951 when Rochester Area Multiple Sclerosis was founded by Sigl, Benjamin and Roman Speegle.

The following year, Rochester Area Multiple Sclerosis (RAMS) became a chapter of the National Multiple Sclerosis Society. Shortly afterwards, the agency hired an executive secretary and obtained a rent-free office in the Municipal Hospital (the Old Rochester General Hospital) located on West Main Street. In 1955, the chapter rented an office at 133 East Avenue, hired a part-time office assistant and joined the Council of Social Agencies and the Community Chest.

The RAMS program was divided into four major areas: administration, education, client service, and research. Client services focused on the understanding of the disease and how it imposed strain and hardship on both people affected by the disease and their families.

RAMS began a vigorous public education effort about the problems of people with MS and derived some financial support from radio and television coverage and the publication of <u>RAMS NEWS</u>, a monthly newsletter. <u>RAMS NEWS</u> routinely featured articles about the disease and progress in treatment as well as updates.

RAMS supported the National Multiple Sclerosis Society in scientific research by forwarding forty percent of its receipts to the national organization. RAMS also supplied the national organization with statistics and provided clinical material for research projects at the University of Rochester Medical Center.

From a handful of members in 1952, the organization had grown by 1955 to 630 members, 247 people with MS, 69 relatives, and 314 interested citizens. Monthly general membership meetings struck a balance between education and entertainment for the attendees.

In 1957, RAMS moved to 50 Prince Street, close to the Rochester Rehabilitation Center and in the same building with the Medical Motor Service, both of which provided services to RAMS.



In 1967, Executive Director of Rochester Area Multiple Sclerosis, Barbara Flanagan (far right) went to city council meetings to urge the council to amend building codes to facilitate access and support independence for people with disabilities.

RAMS remained a staunch supporter of the National Multiple Sclerosis Society, giving a large percentage of funds raised each year to the National organization to help fund MS research. The agency sponsored many local fundraisers including READ-a-Thons in local schools with children collecting pledges for books read.

A major gain towards independence in the area of handicapped accessibility issues was made in the 1960s, when RAMS, as part of a coalition effort, lobbied City Council to consider public access. In a late-night session in January of 1967, City Council members voted to change the building codes to make special provisions for the handicapped in new buildings. Barbara Flanagan, RAMS Executive Director, stayed until the early morning hours to see the vote through.

By 1968, when RAMS moved into fully handicapped-accessible facilities at the Al Sigl Center, the agency was providing service to more than 700 people with MS. Neurological care, social programs and respite care programs for families were developed. Though facilities at the Al Sigl Center were handicapped-accessible, RAMS mission and focus was out in the community providing education for people with MS and for the public about the disease, developing social and recreational programs for its members and supporting research into the causes of the disease.

In 1971 the RAMS summer camp program began and offered a week at a camp fully staffed by nurses, other professionals and volunteers who provided full care for clients while also providing a respite for caregivers at home. Since 1985, RAMS has sponsored a winter camp as well.

In 1976, Executive Director Virginia Hartley developed a survey to assess the needs of people with MS with a view toward the agency's program expansion and modification. Outreach workers began to serve people in Wayne, Livingston and Ontario Counties.

By 1979, a combination of outreach programs and current agency membership made additional social work services a necessity. An active and enthusiastic corps of one hundred volunteers continued to assist the agency with daily programs, special trips, camp, office work, READ-a-Thons etc. A part-time volunteer coordinator was hired to oversee and enhance these efforts as well as offer recognition and support for the growing number of volunteers.

In the 1980s, RAMS staff became very active in the community, coordinating efforts with other professionals to develop more resources for people with MS. RAMS also began drawing the Rochester community in to participate in National Multiple Sclerosis Society events. The MS 150 Bike Tour and the MS Walk are two major events still supported annually by this community.

Supported by research completed in 1990 and by a commitment to delay institutionalization for many of their clients, RAMS moved to develop phase one of their Long-Term Care Program, a Day Health program in partnership with Park Ridge Health Systems. This program was designed to bring medical, clinical and social services to clients as well as to offer respite for families and caregivers.

RAMS goals, services, and commitment have changed little since the start. Providing programs and services to people with MS, educating the general public, and supporting research into the cause and prevention of MS have remained constant.

Mary Cariola Children's Center: Children First

"Always think of the children first."—Mary Pulvino Cariola

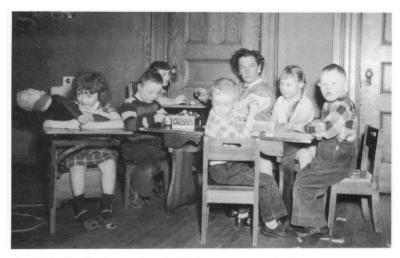
In May of 1949, Jeanette Borelli, mother of Anthony, a child with multiple handicaps, prepared a spaghetti dinner at her house for six parents of children with cerebral palsy and Mary Cariola, Anthony's aunt. Dinnertime conversation was about how to help their children accomplish what they believed was possible; that the children could learn, grow and lead a full and rewarding life. At that time, there were few services for children with multiple handicaps. These parents and family members met to attempt to develop quality educational and recreational programs. It was the first step in the development of the Day Care Training Center for Handicapped Children, an agency that became the Mary Cariola Children's Center. It is believed to be the first parent-initiated, parent-organized day care center for children with multiple handicaps in the United States.

In 1949, the idea of providing quality programs for multiply handicapped children was a radical thought, considered a waste of time and resources by many. Undeterred, this group found donated space in the Eagles' Hall at 22 North Washington Street. They held card parties, spaghetti dinners and bazaars there to raise money for programs for the children. Mary Cariola solicited the support of community organizations and at one point the Monroe County Hotel and Restaurant Association sponsored a coin bank drive which netted over \$1500 for the project. For the first two years, the pay for the project's one teacher came from donations. Lawyers, plumbers, and doctors donated their time.

The Day School for Handicapped Children opened on October 10, 1949 with five children, one paid teacher, volunteer parent aids and pediatric services by the city health physician. Mary Cariola herself was guide and inspiration. By the end of the school year, there were twelve children enrolled.

In 1952, the Day Care Training Center for Handicapped Children was incorporated as a non profit organization. For the first time, the new center received Community Chest support of \$15,000.

The following year two more rooms were refurbished to serve 65 children. The Lake Avenue Baptist Church donated space in 1956 for two nursery school groups of children four to six years old with multiple handicaps. In 1958, the Center bought their own space at



In 1951, the Rochester Board of Education gave the Day Care Training Center for Handicapped Children (now the Mary Cariola Children's Center) permission to use two classrooms at School #17 on Orange Street. Before educational programs were established for children with developmental disabilities, volunteers and parents like Geraldine Werner (center) offered love, care and attention to the physical needs of the children in a classroom setting.

1530 East Avenue thanks to 630 volunteers who raised the necessary \$75,000. In these early years, parents and friends were the transporters, cooks, renovators and more.

In the beginning years, most of the children were mildly to moderately retarded. As more severely handicapped children were enrolled, an intensive care program was developed including physical therapy. Programs focused on self-help skills, socialization skills, simple food preparation, hygiene, and appropriate behavior. The first physiotherapist was Don Ciaglia who eventually became Executive Director in 1959 and remained in that position until 1971. One of the agency's major goals was to get children out into the community to share the pleasures of childhood that other children could experience.

In 1968, the Day Care Training Center moved into the Al Sigl Center with a staff of forty and 180 children and again, quickly outgrew the space. The older children, by now enrolled in the education and training program, went to classrooms at Monroe Developmental Services while the school age and preschool programs and administrative offices remained at the Al Sigl Center.

The Center's student population grew in the 1970s as more children with more severe mental retardation were admitted to prepare them for programs that were beginning in city and suburban public schools. Donald Burke was Executive Director when in 1975, public laws were passed guaranteeing all handicapped children the right to an appropriate education. New laws mandating that all teachers be certified forced a change in educational focus and in staff, which had included many parents and paraprofessionals.

In 1977, the Board of Directors, wishing to honor Mary Cariola for her absolute commitment and full-hearted volunteer involvement in every aspect of the cause of improving the lives of these special children, renamed the Day Care Training Center for Handicapped Children the Mary Cariola Children's Center (MCCC).

Support for parents had been a pervasive part of Mary Cariola's vision. In the 1950s and 60s, she was an advocate of respite care that would give a family time to relax after the difficult task of caring for a child with special needs. The concept of an Intermediate Care Facility (ICF) Program developed for adults by the State of New York seemed a good place to start.

In 1979, after years of studying laws and funding mechanisms and interacting with neighborhood groups, a community residence for eight children was opened on Browncroft Boulevard in Penfield. It was the first such residence outside of the New York City area and the first ICF for children in Monroe County. Despite neighborhood resistance, it became a model for other agencies to follow. In 1982, a residence opened in Greece, in 1984, one in Perinton, and in 1991 one in Rush.

In the 1980s, the trend toward community-based programs rather than institutionalization increased referrals to MCCC. The agency served growing numbers of autistic children, children with severe multiple handicaps, and those with mental retardation and behavior problems. Two new wings added over 60,000 square feet for the agency to the Al Sigl Center Elmwood Campus in 1982 and 1987 to accommodate this growth.

In the late 1980s and early 1990s, MCCC was challenged to provide new programs for increasing numbers of children who were helped by the enhanced hospital neo-natal intensive care programs. Programs for in-home screenings of increasing numbers of drug-affected infants and toddlers were developed with Monroe County Foster Care. Adaptive therapy equipment was constantly being developed for the individual needs of the children in the agency's many programs.

By always thinking of the children first, Mary Cariola and the parents and friends who gave so freely of their time and talents won the right for their children to learn and grow to their potential.

The Association for Retarded Citizens: Integration and Independence

In the early 1950s, Robert and Winifred Wagner placed an ad in a Fairport newspaper inviting families of children who were mentally retarded to meet to discuss education and opportunities for their children. The Wagners had two mentally retarded children and knew of other families in Fairport who were facing the dilemma of trying to educate children who could not learn in the traditional way. Since schools were not required to provide educational programs for children with mental retardation, the choices for families were either to accept institutionalization at Newark State School or keep the child at home with no socialization or learning other than what the parents could provide. Mrs. Wagner, who was a teacher, began "kitchen classes", teaching four to six of the children between the ages of four and ten years old at her home. Parents also planned and organized social and recreational activities for their children.

What is now the Monroe County Association for Retarded Citizens(ARC) began in 1950 as The Sunshine League under the leadership of Ben Gold. The membership was largely made up of parents who worked tirelessly to provide educational, recreational, social, and job-related activities for individuals with mental retardation and developmental disabilities in Monroe County. In 1956, at a meeting in the Powers Hotel, more than 150 people voted to unite efforts for all people with mental retardation in the area in an organization to be known as the "Sunshine League" for Retarded Children, Monroe County Chapter of the Association for Help of Retarded Children." That same year, the League became a chapter of the New York State Association for Retarded Children, Inc. of which Robert Wagner was the first president.

By joining the state chapter, the Monroe County Chapter gained a stronger voice on leglislative issues that would pave the way for the development of programs and services fostering independence for people with developmental disabilities and mental retardation. With Robert Wagner as president, Emmet McCorry and Frederick Diehl as vice-presidents and Celia Mittleman as treasurer, this small group of

parents took the first step toward their dream of having sons and daughters with disabilities live in the community and have the same rights as other citizens.

In 1958 ARC began a small day activities program for twelve people in the basement of Rochester General Hospital on Main Street and a year later, with a grant to fund a work training center, ARC began to offer direct services to clients.

Always with the goal of helping adults with developmental disabilities achieve their highest level of independence, ARC opened its first sheltered workshop, the ARC Work Training Center, in 1959 on College Avenue. After the workshop moved into Buonomo's Bowling Hall at 178 Charlotte Street, sixty adults were employed doing piecework, like assembling switches for Eastman Kodak Company and peeling vegetables for the East Avenue Sheraton Hotel's kitchen.



Adults with mental retardation assembled fishhook holders for Ontario Plastics, Inc. at an open house for parents and family at the Charlotte Street Workshop in 1959. The Association for Retarded Citizens' sheltered workshops provided paid employment, a step toward independence for adults with developmental delays.

In 1968, when ARC moved into the Al Sigl Center, the number of clients doubled, the workshop grew to 120 and daily activities clients to 60. The following year, ARC parents were already asking about plans to increase program space as they were already reaching maximum potential.

Parents increasingly began to look for alternatives to institutionalization. As a general nationwide movement toward deinstitutionalization grew, ARC took on the lengthy bureaucratic process of buying and renovating homes in the community for client housing. Neighborhoods did not welcome people with mental retardation into the community residences. Many negotiations and meetings were held before ARC's residential program began in 1969 with the opening of a community residence at 191 E. Henrietta Road, one of the first in the state.

From 1970 to 1979, Monroe ARC opened seven community residences and one sheltered employment program, began the horticulture program and opened a day treatment program. The Work Training Center opened on East Ridge Road in Irondequoit employing more than 200 workers who did jobs like rewinding knobs for Kodak Instamatic cameras and packaging for Mobil Chemical. Monroe County ARC was one of the few providers of Day Treatment Services in the state. Day Treatment Centers at Ballantyne and Crittenden Roads and Clinton Avenue offered a more intensive level of care by providing a broad range of interventions and activities to help the individual progress to an optimum level of functioning.

ARC relied heavily on volunteers. They ran bowl-a-thons, bake sales, wine-tastings and other fund-raisers in support of the agencies programs and mission. The Youth-ARC recreation program, a model project, was introduced in 1970. High school and college student volunteers "buddied up" with youth with disabilities ages 6-21 for a program of recreational and social activities.

Under John Regan's leadership as Executive Director from 1963-1979, program expansion increased the number of people served from 160 to 1000 and the size of the staff from 12 to over 150. In 1976, the agency's Board of Directors voted to change the name from the Association for Retarded Children to the Association for Retarded Citizens to more accurately reflect the population it served. ARC developed businesses like ARC Floral and Deliworks which provided work opportunities to people with mental retardation and developmental disabilities.

From 1980 to 1986, two more community residences opened, and three intermediate care facilities, a transitional employment program, two sheltered workshops and two more day treatment programs began. In 1986, more new ground for ARC was broken with the opening of two Intermediate Care Facilities, a more intensive level of care for severely and profoundly retarded adults. Training in activities of daily living and a plan for rehabilitation focused on the specific needs of each individual resident. In 1986, the Rehabilitation Act Amendments were passed. These increased the emphasis on vocational assessment, training and independence for program participants. Increased emphasis was also placed on moving individuals from sheltered to supported employment.

Throughout the 1970s and into the 1990s, ARC developed a network of sheltered workshops, day treatment centers, and community residences and the agency focused public attention on the needs of people with mental retardation and developmental disabilities. ARC's emphasis remains on integration and independence - an independence that began back in 1956 when parents of children with mental retardation banded together to win for their children what any other child could have.

Epilepsy Association of Greater Rochester: Acceptance and Understanding of Seizure Disorders

In 1977, Patricia Ladd had questions and concerns about her daughter's seizure disorder. The child's seizures occurred without warning and were frightening to watch. Teachers found her daughter's disease difficult to cope with in the classroom. Mrs. Ladd feared that the symptoms, prescribed medications and negative social response to the condition would affect her daughter's normal growth and learning. Knowledgeable, empathetic physicians and health care professionals were hard to find, family relations became strained, and Mrs. Ladd felt that there were few options for her child.

She was employed by Xerox Corporation and applied for and was accepted into their Social Service Leave Program. The program paid her salary for one year while she worked with community resources to investigate the possibility of developing health care resources for people with seizure disorders and their families.

Initial support for her ideas came from the Health Association which

offered office space, supplies and leads to neurologists who provided specific medical information. She tried to locate parents of children with similar disorders but finding them was difficult. Seizure disorders were often viewed as a diagnosis secondary to other social, medical or emotional problems, and services specifically for those with seizure disorders did not exist. Because of the stigma associated with the disease, people were unwilling to step forward. Even though she had the help of Dr. Maurice Charlton and Dr. Frederick Horner, they could not reveal the names of their patients, only inform them of her intent. Outreach was therefore established via word of mouth and several local newspaper articles.

Eight families formed a self-help group to share information and concerns, and quickly identified the need for additional services in the community. With Mrs. Ladd as the unofficial leader, the group determined their goals would be to exchange comprehensive information about cause, signs and symptoms, treatment, and medication for various seizure disorders, to offer emotional support for parents and people with seizure disorders, and to establish needed services within the community.

They used the newspapers to announce their first public meeting in September 1976 and used Dr. Charlton's office as their base of operations. Prior to the meeting, Dr. Charlton suggested that the group consider becoming a chapter of the Epilepsy Foundation of America (EFA). For one third of the local chapter's income and membership dues, the EFA agreed to provide information about how to establish a non-profit, voluntary organization in the Rochester area. The EFA sent a list of organizational criteria that had to be completed before full acceptance could be granted. Full acceptance by the EFA required a nucleus of 20 interested persons, a meeting place, a name that could be published, and a bank account of \$250. By the October meeting, the group had officially become the Greater Rochester Chapter of the Epilepsy Foundation of America(GRCEFA).

In May of 1977 GRCEFA incoporated as the Epilepsy Association of Greater Rochester (EAGR). Early programs included information, counseling and referral programs, parents' support groups, school alerts, a young adults' committee and group therapy for adults with epilepsy.

By 1978 it was apparent that demand for services had outpaced the chapter's ability to provide them, both logistically and financially. Research showed it was possible that there were as many as 7,000 people in the Rochester area that might need support and programs

for seizure disorders, the "hidden disease", but that they wouldn't all come forward for help. In order to expand services, the chapter needed financial support, a stable and visible base of operations and a professional full-time staff.

Funding was, at first, a problem. By August of 1978, a grant application submitted to the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) to initiate a community-based agency serving Rochester and surrounding counties was approved.

In February of 1979, Jean Streppa was named Executive Director. The agency began its full program of information, referral and educational services. Through the early 1980s, with grants from state and county agencies, a comprehensive family support program was developed. School programs, community information sessions, monthly programs with speakers, and recreational events were offered to school and community health providers, employers, children and families. In 1985, the Supportive Apartment Program began, offering a short term transitional program to prepare people for independent living.

In 1980, EAGR's Board of Directors recommended that the association pursue membership in the Al Sigl Center to "strengthen the existing linkages with the current member agencies serving persons with seizure disorders." In 1986, EAGR became the eighth member agency of the Al Sigl Center, the first additional agency to join the Al Sigl Center since its incorporation in 1962. In 1990, EAGR moved into new office space at the Al Sigl Center Winton Campus.

In 1992, EAGR began its summer camp program. Children who had never been away from home because of their seizure disorders attended a week long camp staffed by volunteers and professionals trained to care for them.

The agency's mission in the 1990s is to "enable people with epilepsy to understand, manage and cope successfully with their disorder, and to further public understanding, reduce stigma, and increase acceptance of people with epilepsy." In 1991, EAGR served 2,596 people, offering information and referral, education and training, counseling and support services, employment training and placement services, and a supportive apartment program. The first resident of the Supportive Apartment Program was Pat Ladd's daughter.



A unique part of Epilepsy Association of Greater Rochester's instructional component has been a puppet program called the "Kids on the Block", an educational format designed to help children accept and understand people with epilepsy.

The Al Sigl Center Vision in 1993

In 1992, 27,000 children and adults with disabilities came to the original Elmwood Campus and the new Winton campus for help. The combined operating budgets for all the agencies were over \$40 million, quite a change from 1968 when all budgets totaled less than \$1 million.

"For 25 years, the Center has been in the forefront of societal trends for community-based services to people with disabilities," said Dan Meyers, first Executive Director and President since 1987. "More than just a building where people get needed service, it has been a concept of cooperation, an environment that encourages abilities and independence, a family-driven effort that has become a community-wide gathering of hearts."



(Above) In the 1940s, learning to walk at the United Cerebral Palsy Association then located at 1570 East Avenue.

(Below) In the 1990s, learning to drive in a specially equipped van at the Rochester Rehabilitation Center.

