AND NOW LET'S BUILD A BETTER WORLD:
THE STORY OF THE ASSOCIATION FOR THE HELP OF RETARDED CHILDREN, NEW YORK CITY
1948 - 1998

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DEDICATION

To Anne Kraus, a founding member of AHRC who passed away during the period of this writing. To Anne, to all the founding parents who have gone before her, and to those time has not yet claimed, I dedicate these pages. Through her life and those of the others, through what they achieved by extraordinary dedication to their children, let us all be reminded that we are but temporary residents here with a basic responsibility to help build a better world.

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"Faithfulness to the truth of history involves far more than a research, however patient and scrupulous, into special facts. Such facts may be detailed with the most minute exactness, and yet the narrative, taken as a whole, may be unmeaning or untrue. The narrator must seek to imbue himself with the life and spirit of the time. He must study events in their bearings near and remote; in the character, habits and manners of those who took part in them. He must himself be, as it were, a sharer or spectator of the action he describes." -- Francis Parkman, Pioneers of France in the New World, (Introduction), 1865.

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CHAPTER 1 - A SHORT HISTORY OF THE TREATMENT OF PERSONS WITH MENTAL RETARDATION

> "The subject of history is the life of peoples and humanity. To catch
> and pin down in words-- that is to describe directly the life, not only
> of humanity but of a single people, appears to be impossible."
> Leo Tolstoy, **War and Peace**.

The purpose of this chapter is not to try and capture the history of people with mental retardation in any sense. It is, instead, a way to set the historical stage for the post World War II growth in the United States of the associations of parents who had children with retardation. With this in mind, the early history of persons with mental retardation will be mentioned briefly. In later sections the modern history will be detailed, especially the post-World War II era when AHRC was organized.

Early Treatment

Although the construct of mental retardation is a relatively new one, there have of course been persons with this condition from antiquity. And, while our historical understanding of these persons treatment is quite limited by lack of evidence, it is known that people with handicapping conditions occupied the following kinds of 'deviant' statuses in European and American societies: object of dread, object of ridicule, changeling, evil/possessed person, sub-human organism, diseased organism, eternal child, and holy innocent (see Wolfensberger, 1972). While the dominant status in contemporary society was, and remains to some degree, that of diseased organism (the so-called "medical model"), all of the above ways of perceiving persons with mental retardation still exist in various degrees in contemporary society, and continue to influence our treatment of these people and their families. They are 'historical ghosts' that still inhabit our thinking and behaviors even though we scarcely understand them or their origin.

The Institutional Care System

The particular history of mental retardation in the United States (called "feeble-mindedness" and "mental deficiency" in the 19th and 20th centuries) has been told eloquently in several sources, including Trent's recent (1994) award-winning account. It is generally understood that scientific concern for the care of people with mental retardation resulted from the efforts of the French Encyclopedists of the 18th century in whose work concern for the welfare of various oppressed peoples was primary. The first work with mental deficients was attempted at the end of the 18th century in institutions such as the Bicetre or National Institute for the Deaf and Dumb in Paris. In fact, it was at the latter Institute that Jean-Marc Itard met Victoire of Aveyron, the so-called "Wild Boy of Aveyron," and began what is regarded as the first documented case of special education. It also turns out that Itard's best student was Edouard Seguin. Both these men shared the belief that much of the intellectual functioning of persons with mental deficiency was not innately limited but could be developed by training. Seguin opened a school for mental deficients in France in 1848, but fled the country after the Revolution of that same year, emigrating to the United States where he remained active and profoundly influenced the care of 'mental defectives,' advancing his philosophy of care known as "moral treatment."

In the United States Samuel Gridley Howe had been an early experimenter in the care of children with mental retardation, actually training blind children with this condition since 1838. With his help a special experimental school had been begun by the Perkins School in 1848. But the first legislation to establish special schools for people who were mentally defective was enacted in New York in a Bill sponsored by Senator Frederick Backus in 1848, enacted in 1851. This led to the creation of the New York State Asylum in 1851, headed by Henry Wilbur. The site where this Asylum was established became eventually known as the Syracuse State School, and today the Syracuse Developmental Disabilities Services Office.

In 1876 the directors of institutions for the feeble-minded, as they were also referred to in this era, formed a national professional society, the Association of Medical Officers of American Institutions for Idiots and Feeble-Minded Persons, which eventually became the American Association on Mental Deficiency, and today the American Association on Mental Retardation. This Association largely determined the medical and rehabilitative treatment of persons with these conditions for the next hundred years, and continues to be influential today. What they originally wanted was to establish institutions for those who were not so severely handicapped that they were unable to live in their community. That is, they wanted to be able to train the students and discharge them once they had learned what it was that was necessary to live in the community. Howe makes this kind of philosophy clear as early as 1848, although this is not how things actually worked out. For example, at the Syracuse Asylum only "boys and girls of the higher grades" (what was eventually called "educables") were admitted. But, the results of their education were not encouraging. In addition, there were few or no community resources for parents with these children and as Lerner (1972:23) wrote, "Parents of children who had reached the age designated for release to the community pressured the schools to keep their children. In addition, there were appeals for admissions of new cases of all ages and with all types and levels of mental defects." The role and size of institutions expanded well beyond what had been considered desirable by their founders earlier in the century. In New York towards the close of the 19th century we had in addition to the Syracuse Asylum, a branch of the Syracuse Asylum opened in Newark (New Jersey but serving metropolitan New York), a hospital and school on Randall's Island in New York City, and Rome State Custodial Asylum. These places were basically the options available to parents during this period of history. While there were some small private schools, and a tradition of teachers of special children who boarded a small number of them in their homes, these were expensive and essentially unavailable to any but the relatively wealthy.

Initially 'institutions,' 'schools,' or 'colonies,' as they were originally called, operating under a philosophy of treatment and training, attempted to provide relatively normal living conditions, educate residents, and provide opportunities for them to work on grounds if they were not released. These places were not simply dumping grounds that we associate with institutions in the 20th century. But over time their character changed for the worse. There were several reasons for this including the invention of the philosophy of eugenics in the latter part of the 19th century. This philosophy combined the religious tradition of degenerationism (that people with disabilities were marks of evil and sin) with the sciences of genetics and evolution. What emerged was a kind of social Darwinism that saw the evils of society as genetically based. Mental deficiency, criminality and delinquency, prostitution, and alcoholism were seen to result from the defective genes of the individuals. This led to a movement of sterilization of mentally defective persons, especially women, that was strongly advocated by medicine and government (for example, Oliver Wendell Holmes was a strong advocate of sterilization). Indeed, sterilization was presented to the public as a humane way to address these social problems. This is especially true considering that the other part of the eugenics program was a euthanasia movement advocating the killing of mentally defective babies and children. In Germany, euthanasia became official medical policy sometime around 1920, and was openly taught and practiced in medical establishments of all types (see especially Friedlander, 1996; Wolfensberger, 1981). But in the United States, while euthanasia never became official medical policy, it was practiced and openly advocated. Martin Pernick's 1996 book The Black Stork describes the Baby Bollinger case of 1915 and the efforts of Dr. Harry Haiselden, including the making of a feature length film "The Black Stork," to institute the medical practice of euthanizing children with disabilities. The euthanasia movement in the United States was not a lunatic fringe movement. It was well publicized in newspapers and media, and strongly promoted by professionals. This can be better appreciated when one considers that during World War II, the American Psychiatric Association published a lead editorial of their journal that endorsed the legal euthanasia of mentally retarded children and the provision of psychotherapy to parents to relieve them of their guilt (Wolfensberger, 1981).

These attitudes in medicine and other scientific disciplines strongly influenced the treatment of persons with these conditions throughout the 20th century, and as the reader can appreciate from the date of the American Psychiatric Association editorial, were still very influential around the time that many of the founding parents of AHRC had their children. But the immediate effect of these ideas was to transform the nature of institutional care. In New York the institutions that had been built to train, habilitate and release persons became places where they went to live forever. Those who were 'genetic' types and who had severe forms of disabilities were seen as completely custodial and efforts to train them were largely abandoned. Those in institutions who were high functioning and were trainable did receive training but largely to occupy roles of institutional peonage, that is, to work on the institution grounds as free labor. Few actually were released to the community.

All these changes occurred under the supervision and surveillance of government and professionals. A State Commission for the Feeble-Minded that had been formed in 1918 to oversee institutions in New York State became in 1919 under State law the State Commission for Mental Defectives. Finally, in 1927 the Commission became part of the State Department of Mental Hygiene, the Department that controlled institutions through the 1970's. Under the Department of Mental Hygiene institutions in New York expanded in number and in census. In 1907 Letchworth Village was established in Thiels, New York. In 1930, the Wassaic

School was opened. At the same time Randalls Island was closed in 1935, and the Willowbrook State School, scheduled to open in early 1942 was taken over by the Department of the Army and converted to Halloran Veterans Hospital.

To complicate matters further, with the Depression in the 1930's and the War in the 1940's, fiscal resources dried up and institutions had fewer staff who were less trained. They also were beginning to get very crowded. Children below the age of five could not by law be placed in institutions at this time, but the group of children under age 10 had been steadily growing since the 1930's, partially at least, as a result of medical recommendations to remove the idiot child from the family for the family's mental hygiene. By 1943, 32% of beds in institutions were filled by children aged 5 to 10 years. By 1945, the five state schools housed 15,631 patients even though the planned census had been for 11,713. The Schools became very over crowded, Letchworth Village reported to be 20-30% overcrowded, with 200 children sleeping in living rooms and on mattresses on the floors. Partially in response to these conditions, the State government set up a Commission to examine problems of mentally ill, delinquent and mentally defective children. It cited under staffing in institutions, the inability to get children in institutions, and the failure to provide non-institutional care as the primary issues facing this population at the time. The Commission proposed legislation that was supported by the New York Times and Liberal Party in New York State. However Governor Dewey proposed alternative legislation involving delinquency issues, with which the country was preoccupied after the War, and the issues of retardation were again pushed into the background.

It was in 1945 that State Schools began admitting children under five years of age. This was seen at the time as progress and help to parents of severely disabled children. The then Commissioner of the Department of Mental Hygiene, Dr. Frederick MacCurdy, announced that as soon as the facilities at Willowbrook State School were available, limited numbers of infants could begin to be admitted.

However, the Department of Mental Hygiene failed to anticipate the reluctance of the Veteran's Administration to give up the facility. Indeed the Governor wrote letters to the Army complaining of the crowded conditions that existed in the State Schools and lack of placements for infants, for whom the State had a waiting list in 1946 of 800-900 (although he did understand the priority given to veterans and mentions that the enemy would have liquidated retarded children and adults). The Governor's letter to Omar Bradley also evidenced a concern with the parents of retarded children, many of whom were themselves veterans. The outcome of this confrontation was that the Army agreed to leave the facility, planning to do so in 1948 but making space available to the Department of Mental Hygiene the next year, 1947. It appears that residents did begin to arrive at the end of the 1940's (some I have interviewed recall the uniforms of the doctors and nurses who were there when they arrived). But it was not until the early 1950's that Willowbrook was actually used to alleviate the crowded conditions at the other State Schools.

At exactly the time when AHRC was being formed, Edith Stern, a reporter of that era who did several articles on the topic of children with disabilities, published an article in the August, 1948 edition of **Women's Home Companion** entitled "Take Them Off the Human Scrap Heap." Numerous descriptions were offered of deplorable conditions similar to those made famous by Geraldo Rivera in his exposé of Willowbrook State School some twenty-five years later. Articles about these conditions and the resulting incidents of death or ill-fated escapes appeared in the newspapers and were known to the public who for the most part remained indifferent. Sterilization had become a routine and expected part of placement for women.

Such was the effect of expert knowledge on the treatment of persons with mental deficiency in institutions during the first part of this century.

The Educational System

A slightly different story needs to be told about the public education system and this population. Interestingly, special classes for children with mental deficiency had been established in some states as early as 1870 and in New York by 1902. The development of special classes was spurred on by the new profession of psychology, particularly by the work of Alfred Binet and Theodore Simon who constructed a method to test intelligence. This method was brought into the United States and refined by such persons as Dr. D. L. Terman who constructed the Stanford Scale and Dr. Henry Goddard who authored the Vineland Scale. Such tests were widely accepted in the United States and were employed in the school systems. Their application revealed a new class of mentally deficient child, the so-called moron, who were children that were later called "high grades, "borderlines" or "educables" and for whom there had been previously no educational programs. There were large numbers of these children, who had previously been called "laggards" and were seen as burdens to the educational setting. The new tests showed that these children had subnormal I.Q.s and that they lacked the capacity to participate in regular classes. Thus the special classes begun in school systems across America during the end of the 19th and beginning of the 20th century were for such children.

The attitudes of society for these less afflicted individuals appears to have been considerably kinder than for their more handicapped counterparts. By 1917 New York had passed laws mandating classes for those educationally eligible. (Parents with children not meeting educational qualifications could keep their children at home until they were eligible for residential placement at a state school or training center). In New York City considerable progress had been made by 1921 in opening classes for educables, some 258 existed with an enrollment of 4,896 students. While this fell considerably short of the need, estimated to be 1000 classes to serve all the children thought to be eligible under the laws provisions, it is clear that early in the century some progress was being made in opening up the educational system in New York City to people with 'mild mental retardation.'

Progress slowed for many reasons, including monetary since the depression and World War II also had fiscal effects on social services other than institutions. There was a severe shortage of trained teachers, and educators were not quick to understand the educational requirements of special classes. Despite these and other problems, special classes in the New York City School system, under the aegis of the Bureau for Children with Retarded Mental Development (BCRMD), increased steadily over time. By 1946, in the years just preceding AHRC's founding, there were 669 special classes with 11,938 students, in accordance with the requirements of State law that classes be provided for students between the ages of 5 and 12, with I.Q.s between 50-75. Most of the classes in the State were in New York City.

Even with the growth of special classes in New York City, the need far outweighed the available services and many children with moderate mental retardation remained in regular classes or did not attend school. Those in regular classes were not "included" in today's sense of the term. Instead, at this time they were described as "trapped" in regular classes in which they tended not to have their educational or social needs met. Further, literally nothing had been done in New York to meet the needs of children who fell below the educational standards set by State law. No public educational services were available for this population.

There were some private schools that did provide education for children with more complex educational and developmental needs. The Parkside School in Brooklyn, the Seguin School in Newark, and the Kolburn School in Connecticut were such examples. And there were also individual teachers who would board children in their homes and teach them. These arrangements, however, were quite expensive and essentially unavailable to the average family. Just before Ann Greenberg founded AHRC she had sent her son Jerry to the Kolburn School. In order to do so, the Greenbergs had decided that Ann would go back to work full-time, in order to pay for Jerry's schooling.

So this was the situation that parents of children with mental retardation faced in New York City at the end of the 1940's. Institutions were overcrowded, classes for the children considered educable were inadequate in number, no education (outside of State School) existed for children who were not eligible for CRMD classes, and there were also almost no services, other than State School placement, for persons with retardation after they turned sixteen. The immediate post-war years did not see any substantial improvements in the care of retarded children.

Both the parents and professionals acknowledged the lack of services and supports for this population. Professionals such as Dr. Lloyd Yepsen, the President of the only professional organization, AAMD, and George S. Stevenson, medical director of the National Committee on Mental Hygiene, were clear about their condemnation of lack of services both institutionally and in the community. A famous psychologist of that era who was to play a role in the founding of AHRC, Dr. Helen Thompson of the Pre-School Development Clinic in New York City, was outspoken about the lack of services for those parents who wanted to keep their children at home. These and other professionals were part of the stirrings of a new social consciousness about the treatment of persons with mental retardation. They saw the field of mental retardation as being at a very low point, suffering from scientific pessimism and neglect (the dominant psychiatric view that mental retardation was permanent and incurable), lack of trained personnel and facilities, isolation from other human services, and a reputation of "hopelessness."

Under these historical conditions parents began to develop a new sensitivity to their children's situation, and a commitment to change it.

The Formation of Early Parent Groups in the United States

The final topic I will cover in setting the historical stage for the development of AHRC is its relationship to other parent groups that preceded it. While it is well documented that AHRC was a leader in the parent movement, it was not the first parent group to form around the interests of their children with mental retardation. As Elizabeth Boggs said in an interview in 1972, generally the first groups recognized for such efforts are groups associated with children in particular institutions. The Council for Retarded Children in Cayuga County in Ohio formed in 1932, the Children's Benevolent League, who's motto was "Health, Happiness and Security of Handicapped Children," soon followed in 1934 in the state of Washington, and in New York State the Welfare League for Retarded Children was begun in 1939. The Welfare League consisted of parents of children and adults who resided at Letchworth Village. The group was concerned with providing their children with gifts, recreational programs, and better facilities. The Welfare League, at least during the 1940's, is portrayed in several sources as a small group that was basically apolitical. While this was to change in the 1950's, The League, before and during the formative years of AHRC, was not a political force in the state for children with mental retardation.

The same year as AHRC was incorporated, the Benevolent Society for Retarded Children was formed to help children who had been placed in Willowbrook State School. Three years following this, the Sunshine League for Retarded Children came into existence around the interests of children in Wassaic State School. The institution-based parent groups did not have a statewide organization and did not become a political force in the state until after AHRC was formed and began intensive political and public awareness efforts. In response the institutional-based parent groups then formed the Council for Retarded Children and the relationship between the community-based groups and institutional-based ones was very uneasy throughout the 1950's until they resolved their differences.

The important thing for the reader to take away from this discussion of parent groups before AHRC is that none, including those in other states, were interested in community-based services for children with retardation. Furthermore, none articulated or advocated for a general approach to the problem of mental retardation on a political level. This left the actual decision-making power in the field entirely in the hands of a small group of professionals, and without pressure from parents, they showed little interest in expanding services for this population. Mental health professionals, educators and institution directors were ineffective in dealing with the issues facing most families with a child with retardation. After the war, as a result of the factors and changes described briefly above, the lack of services for these families was remarkable.

The conception and birth of AHRC was in some ways a product of this situation.

CHAPTER 2 - BIRTH

> "We can't form our children on our own concepts; we must take
> them and love them as God sends them to us." - Johann Wolfgang
> von Goethe, **Hermann und Dorothea**, 1797

> "The word "Mongoloid," I had heard the word "Mongoloid," but I really thought it was a monster. I didn't know what a Mongoloid was. And I said, 'Are you going to let me see the baby?' And they did show the baby to me...and she looked alright to me." - AHRC Board Member Thelma Ragland, remembering the birth of her daughter with Down syndrome.

The origin of AHRC is not to be found in its formal history, incorporation documents or public papers. It begins, instead, with the birth of children with mental retardation in New York City during and after World War II. The founding parents' experience of the birth, diagnosis and early years of their children is perhaps the best way to understand why they came to form AHRC. It is indicative of the experience of so many thousands of other parents in similar circumstances at that time. The following brief narratives, constructed from interviews and video tapes, present several founding parents' memories of their child's birth. These are followed by a narrative of a younger couple, one of whom is a member of the AHRC Board today, describing the birth of their daughter with Down syndrome in 1988. While certain similarities between older and younger parents' narratives are evident, the stark contrasts between them leads us to the central questions that will occupy the remainder of this writing. How did society change so as to produce the differences in these generation's experience of the birth of a child with retardation? And, what was AHRC's central role in producing those societal changes?

The Founder's Children

Jerry Greenberg

Ann Greenberg's son, Jerry, was born during the War and was not part of the baby-boom children whose parents were ultimately to become the backbone of AHRC. Jerry was born a beautiful baby without any suspicion of disability from either family or doctors. During the war, while her husband was in the service, Ann lived in her mother's home with her sisters. When Jerry was about five months old, she and her sister went to visit their brother, also in the Army and then stationed at Fort Dix. In a recent interview Ann describes her return home that day.

> "We came back that day, my mother said to me there's something wrong. He seems to be...it looks like he is in pain of some kind. He was about five months old. I didn't know what that meant, but what he was doing was stiffening up. He wasn't losing [consciousness]. He was stiffening up...So then we started with the doctors and hospital, the Presbyterian Baby Hospital. My doctor, who delivered him, and nobody else could figure out what it was. I kept a record of how many times a day this happened...I got $80 a month for the baby...and I was spending it on doctors and nobody could figure out what it was.
>
> One day we went to the Baby Hospital clinic, my mother took me. He never had the episodes when the doctors could see it. So they had to go by what I said. I laid him down on the table and this doctor looked at me and said to me, 'His brain has been injured. He's retarded. Go home and have another baby.' (Pauses) I never forgot him. I looked at him with a face like, you know, I don't understand that. So he repeats. 'Go home and have another baby.' First of all, I can't go home and have another baby; my husband is in the war. Secondly, I am not interested in having another baby, only the baby on this table. So he says,

> 'Well, that's all I can tell you. We can't help him.' And he walked out. I tried other doctors, private doctors, you know there was no clinic for retarded children."

Ann tells of her continuing saga of seeking doctors to help her with Jerry. She was lucky in the sense that Jerry and she lived in a "home filled with love." Jerry had several loving caretakers, she, her mother and her sisters. But despite their efforts, Jerry had serious seizures at about the age of twelve months.

> "I was writing a letter to my husband, like I did every single day, and my mother called me. There is something wrong with Jerry...He had convulsions...I called the doctor up and said, what do I do? He never had this before. He said, 'Put him in the bathtub with warm water.' My mother and I rushed him into the bath with warm water...An hour or so later, it happened again, we did it again. Do you know, that never happened any more, after that."

Whatever the cause of his condition, Jerry developed slowly.

> "It took him longer to walk, it took him longer to learn how to walk. Then he showed all those signs and was hyperactive. If he wasn't hyperactive he'd be alive today. Then the doctors were giving me (pheno)barbital."

Unfortunately this drug was not good for Jerry. He became even more agitated, remained awake for 24 hours, and then was depressed. Ann remembers that Jerry stopped smiling when he had the seizures and was taking phenobarbital. She remembers him starting to laugh again after she stopped giving him phenobarbital.

> "We ran up on the roof, my sister, she's wearing her house coat, half-undressed...we took a picture...He's finally smiling again. She took him, she showed him over her shoulder, I'll never forget that picture. And from then on

> he was himself again."

Despite the family support system that Ann had, including her husband when he returned home from the war, there were no services for Jerry and this made Ann begin a personal campaign of letter writing that, for many reasons, blossomed into the parents movement in New York City-- and eventually took the form of AHRC in 1949. Much of that story will be told in Ann's own words in the next section. What was avoided by Ann for the most part in her interview were the particulars of the tragic death of her son at the age of eight. She was able to say this much, and with great feeling behind her words, as if the event were yesterday and not almost fifty years ago.

> That is when I lost my son...it was a public building [i.e., the building could not be locked] and he walked out the door. By the time they found him it was too late."

Jerry died by drowning. Even though this tragedy occurred and Ann and her husband had another 'normal' child soon after Jerry's death, she remained committed to AHRC and the other parents with whom she felt kinship. At the time of this writing, Ann, in her eighties still comes to AHRC each day to work in the mailroom.

Lisa Pendler

Betty Pendler has been a Board Member of AHRC and has been an active parent in the parents' movement for forty years. She is well known nationally as a parent-advocate and continues to participate in some of the most innovative and interesting projects in the field of mental retardation. She is moving and incredibly honest about her own experiences with her daughter Lisa, who was born with Down syndrome. The following brief narrative is taken from a 1991 AHRC training video, "Communicating with Families."

> "When my husband and I got married we had never heard of the term Down syndrome. We didn't know anything about Down syndrome. This was the first baby and very much wanted baby. But I had three girlfriends also who had married late in life and who had children. And one of my friends noticed that obviously there was something wrong. She suggested that I go to see her doctor instead of the doctor I was using. Contrary to my husband's advice I went to see this doctor and that was a very devastating experience. The doctor held her up like a plucked chicken and pointed to the various symptoms of Down syndrome and then told me that since she was a girl, my husband and I should consider putting her away. I came home that night and I was absolutely devastated. And I remember my husband saying to me, 'Well, I want to ask you Betty, yesterday you didn't know she was retarded and today you do. Is she any less precious to you today than she was yesterday?' And my honest answer was...yes. And I immediately went into throws of depression and all kinds of emotions as a result of that.
>
> "My darkest thoughts were on the first night when we discussed it. And I asked, how I was going to go on? My dreams had been shattered in one fell swoop. Neither one of us had been married before and this was a very much wanted baby. I had dreams of having a daughter who was going to be my friend. And I immediately felt that I wasn't able to go on. I immediately felt how nice it would be if I were dead. I felt how nice it would be if she were dead. And for the next few weeks I went through horrendous emotions. When I took her to the pediatrician I actually contemplated jumping into the pit of the subway. And I remember my husband not believing me when I said to him, when I was giving her a bath in the bassinet, that I was tempted (stammers)

> to fill up the water all the way. Thank goodness I didn't cause Lisa is just a wonderful human being! But those were the emotions I felt at that time."

Betty Pendler was not only able to overcome these early feelings but has been mother and friend to her daughter Lisa, who now lives in an AHRC residence. Betty has been a staunch advocate for her daughter and other persons with retardation. In her speeches she emphasizes how she was often overprotective of her daughter, and how when parents protect their children too much, they are not really helping them at all. In fact, she says, they are hurting their children to protect themselves. Betty is a very self-aware woman, perhaps having something to do with her having been Lisa's parent.

Peter Gramm

Eugene Gramm, parent of Peter Gramm, was a figure in the early years of AHRC, an early elected officer responsible for much of the public relations done in the first years.

The following is taken from a recent interview with Gene about the birth of his son.

> "Peter's mother underwent an emergency Caesarian in the eighth month because of the condition called placenta previa. This could result in the child's death. Peter was born unconscious and blue. He was resuscitated and the general conjecture is that there was deprivation of oxygen to certain centers of the brain that resulted in his retardation...There were no overt signs, no stigmata or anything of that kind. We began to get that sinking feeling that other parents of retarded children know about very early on, when we could see that he lay kind of inertly in his crib and that all the distractions, all those wonderful rattles and toys, colorful and noisy things that bring smiles

> to other infants, had no effect on him whatsoever. So gradually it dawned on us that he was retarded... that was in 1943.
>
> "We went to physicians early on. You know physicians. When things can't be determined they like to take the optimistic view so we had reassurances all the way up to the point where it began to be evident that there was something significantly wrong. The first real blow to the solar plexus was when our general practitioner sent us to a psychiatrist who, in the terminology of 1943, said, 'Your child is a moron.' And then he said, 'Don't feel too badly about the term because we use it in the medical profession.' But I was aghast at the term. Totally ignorant of all this. I'm 78 right now and I was 23 years old then and I said, 'Why do you use that term?' He said, 'Well, there are three terms and your son is in the upper class. We have idiot, imbecile and moron.' Something struck me as being terribly wrong, unmedical and medieval about all that but that was the way it was, as I later discovered when I read the AMA journals. So here we have these two distraught, very young parents with a little boy walking the streets of Brooklyn-- he was now, I would guess, about three years old-- with tears streaming down our faces and totally at a loss, feeling very much alone in the world."

As with the Greenbergs, the Gramm's found no community or residential services available for their son.

> ATHE problem that we began to have as he gained more physical capabilities, even rudimentary speech, was hyperactivity. He became terribly active, hyperactive, and twice, not once but twice, threw himself through the window. Right through the glass pane and everything. Fortunately we lived on the first floor.

> He was so active he had to be tied down in his crib at night and we'd do it with a soft belt from a bathrobe. After a while he would hold up one little leg in order to be tied down that way. As he got older, he was approaching five, he began to shake and even uproot radiators. He had enormous strength for a diminutive boy. It started to become a terrible problem but still one we thought we'd cope with and accept."

But, as Gene said in the interview, life is full of surprises and the almost complete nervous breakdown of his wife was certainly one of these. This occurred in the early 1950's, in the early years of AHRC.

> "I was struggling with Peter and she was having nervous breakdowns and resting in bed. He was uprooting radiators. I had to go to work... (upset) If I could have stayed at home I never would have done that. One of the ghastly mistakes of my life. I didn't know what alternative I had. My family had all fled to California...to this day I still give it a neurotic interpretation.... I finally capitulated and applied to Letchworth Village to get him placed there. There was a long waiting list and I was in a state of crisis. So I went to Jerry Weingold [first Executive Director of AHRC, see below- DG] and Jerry Weingold had some pull at that point but was opposed to it. God rest his soul but he said, 'I don't know what alternative you have Gene, so I guess you have to.'

Weingold was able to get Peter into Letchworth Village despite a waiting list. Gene recalls he and his wife bringing him up to Letchworth when he must have been about ten years old.

> "[We] walked away with his screaming in our ears and they told us please don't come back for at least six weeks. He needed his adjustment time...It

> was a hot July day, it was one of those moments in life that stay with you forever. We both sank down in the grass in front of a church and wept copiously in each other's arms. And we went back and she went back to bed for more weeks..."

While the story of Peter at Letchworth was not a happy one, despite numerous incidents and even being run over by a physician, Peter survived Letchworth. He lived for many years in an AHRC residence and attended AHRC programs (although at the time of this interview he is in a nursing home after a serious fall). It was clear in the interview that Gene still felt tremendous guilt and sadness over his decision. He expressed this most touchingly when he described Peter's poetic tendencies.

> "He has said things that are so wonderful...like when a breeze ruffled the pages of the book we were reading and he said, 'Now the wind is reading my book.'...All these wonderful things he had to say and feel. That's all lost, kind of down the drain." (very upset quickly moves to another topic).

Gene, as many of the founding parents, had many memories that plagued him, and he was still not at ease with what he had decided on Peter's behalf.

A Younger AHRC Board Member's Child

Melissa Riggio

Melissa Riggio is the ten-year-old daughter of Steve and Laura Riggio. Melissa was born in 1988 with Down syndrome. Her father Steve, Vice Chairman of Barnes and Noble bookstores and other book chains, is currently one of the younger parents who serve on the AHRC Board of Directors. Steve and Laura also have an older daughter, Laura who is twelve, and a younger child, Christina, seven. Unless otherwise specified, the following is taken from Laura's narrative.

> "Everything about the pregnancy had been normal. The tests were all normal, so there was nothing to indicate anything was out of the ordinary with the pregnancy. And it was a fairly easy birth. I didn't have to be cut. I didn't need to take anything. Our first was born naturally but I needed to have Demerol and it was quite painful. With Melissa, the birth came more quickly than even the doctor had anticipated. I had to be induced, but I have had to be induced with all three of my children. The only thing at first that kind of alerted me that something might not be right, was at first when they let me hold her, her coloring was not quite right. It was kind of dark. So when I questioned it they said she might be cold and they bundled her up. And then another nurse came in and said, 'Was she born with the cord around her neck?' And I said, 'No.' So they said she might be cold, cause at that point the doctor leaves and lets you bond with them. And I was looking at her, and I noticed, but really did not think anything, that she seemed to have two extra folds in her neck, at the sides. But being a mother I just noticed and didn't think anything of it. I can't say that she had features at that point that would alert us that something was wrong, and I'm a teacher so I think that if her features were very pronounced that would have been something I would have worried about. At that point we were just like bonding, not knowing anything was wrong. And we went back to the room, I think she was born at four, and at six they usually bring them for feeding. At the six o'clock feeding they didn't bring her and we kind of said to ourselves, 'she was just born, maybe they are still working on her, weighing and doing all that'... The doctor came in and said, 'Was there any history of diseases, in your family? Did you take any drugs during pregnancy?' To which I said, 'No' and asked, 'Why, is there something wrong?' He said, 'Well no. The baby seems to have some unusual features

but everything is fine.' Now my pediatrician doesn't practice in that hospital and I was using a neonatologist to come in and examine her, but he wasn't available till the next day, so we were kind of on our own at that point.

"By the time the second feeding came, after him asking those questions, something went off in my head that something is amiss here. And when I walked to the nursery I noticed a lot of people poking and prodding her. And when I questioned them they said, 'No, no. Everything is fine. We are just examining her. And I remember saying to Steve, 'I think something is wrong.' And he said, 'Oh no she's fine. She's beautiful.' But by the second feeding I am frantic. And my obstetrician sees me in the hall and says, 'What's wrong? Why aren't you in with the baby?' And I said, 'Something is wrong. They won't bring her to me.' And he said, 'What do you mean something is wrong?' I told him that they were all looking at her and examining her. With that he told me to go back to the room and that he would be right back. He closed the door and outside proceeded to scream at the Head Nurse that she better get our baby. And they brought her for the feeding. But at that point I was pretty upset. Something was definitely wrong. And when they took her back I asked my doctor what was wrong and he said that they were looking for some syndrome. We are not really quite sure what it is, your neonatologist will be in the next day to examine her. So we had to wait till the next day. At that point Steve was really reassuring -- he kept on saying she is beautiful, she is just like Laura, and nothing is wrong. But I just kept on having this nagging thing. If everything is alright then why are they not bringing her? Why is everyone milling around her?

"And then the next day the neonatologist came, examined her and came in and I said, 'Really I have the right to know. I'm her mother. What is going on?' And he said, 'We think there might be chromosomal abnormality.' And I asked what he was talking about. I went through the list of the few that I knew. But he said, 'I really can't say exactly what it is because your daughter seems to be borderline. She has certain features which would lead us to believe that she has this abnormality. But there are certain other things she doesn't have. And the only way we'll know for sure is if we do this chromosomal study on her.' So they let me go home that day and we had to come back the next day to have the blood drawn for the chromosomal study. And that took about ten days to get the results. And even at that they had promised us that someone would call us within ten days. No one did so I called and they told me that they hadn't finished growing all of the cells. They had only grown ten and they liked to grow sixty. At that point we had already visited our pediatrician, and told him that they want to do this chromosomal study, and he was quite frank the night that we visited him after he had examined the baby. He said that they were looking for '"Mongolism,' which was surprising because he was a pretty young pediatrician and that's a very antiquated term. But he said they are looking for that and that is because there are sixteen features and your daughter has eight that they can see. But the features are so soft that it is very hard from just looking at her to tell. While her muscle tone was low, he had seen babies with looser tone that didn't have Down syndrome. So he recommended the best thing to do is to have the study done.

"So after ten days I call at the clinic and they said they haven't been able to grow sixty cells, only ten. But by that point Steve and I had done some reading and I said, 'Well if it is in every one of the ten cells the likelihood is it will be in the other fifty, we have a right to know. So she said come in and we will have someone tell you the findings. At that point they did tell us, I don't know if she was a social worker or what, she wasn't a doctor. She did sit down and say that it was trisomy-21 and it was in all of the ten cells. She explained it to us the best that she could and then gave us the names of a

> couple of infant stimulation programs and told us that at this point in her life that was really the best thing that we could do. So I think at that point I was upset about it, Steve was really upset about it. But we had already known from the reading that we had done that the best thing that we could do was to get her into some kind of infant stimulation program, as soon as possible. So she literally was accepted into a program and started by the time she was three weeks old.

The Riggios were asked whether they had experienced any shame or guilt after Melissa's birth. Neither did. Laura said that she had taken very good care of herself during the pregnancy and there was really nothing more she could have done in terms of prenatal care for Melissa.

> "I did have feelings of why me? Not guilt or shame, but doubt as to why it happened to me. But I went to the infant stimulation program and I met other young parents and we would talk about it in the parent's support group. I would look around and think, what do we all have in common? Why did this happen to us? What is the missing link? In terms of shame, well, I guess at first I did not know who I could tell. You go through all sorts of stages. You know, you don't want to tell anyone, then you feel like you kind of have to tell everyone. And then you just have to come to terms with it. But I don't think we felt a sense of shame or guilt."

Steve Riggio added,

> "You go from this feeling of why me to very quickly this overwhelming sense of responsibility to take action. Because it is not really why me? It is, why her? She has got the condition not us. But we did feel that we were dealt an overwhelming responsibility and you just have to wake up and face it. No

> shame, but just that we have to do everything we can."

In an interesting comment Laura shared that she had anger, but not at the birth so much as the time they had to spend reading and becoming disabilities experts where they normally would have been able to enjoy their baby. She felt that this part of Melissa's infancy was kind of taken away from her and the family. It took the family a couple of months until they could actually enjoy her, open baby gifts and so on. She admitted a certain amount of depression in coming to terms with Melissa's disability in the first months of her life. But as she came to terms with it Laura felt she should have been happy about her child, the same way as if she had not been disabled.

The Riggio's family accepted Melissa's birth after the initial shock wore off. Steve's mother was very supportive, as were both their brothers and sisters. Melissa went from her infant stimulation program to an inclusion [end note 1] program in a local Catholic school. She is in a regular third grade class and going into fourth grade. Of course there have been problems, as with all children, and Laura says she takes it day by day, working with the school as a team. Melissa has some problems reading, but with the aid of a calculator is keeping up in math. Significantly, she has friends with and without disabilities with whom she socializes regularly outside school. The school is very supportive of educational inclusion and for the five years she has attended the Riggios have never had an experience where Melissa was made to feel that she shouldn't be there. No one ever expressed any resentment or upset at her presence in class. Melissa has thus far had a very normal educational experience for a girl her age. However, the Riggios are moving soon and Melissa will attend a public school in a school district known for supporting educational inclusion. They are hoping that Melissa will continue to have a positive and integrated education along with her peers.

Discussion

All human experiences, from the most trivial to the most profound, have features that are common to everyone, as well as features unique to the particular individuals involved. I have heard many parents of children with retardation over the years discuss what it was like to find out their child had a disability and I never heard anyone refer to it as a joyful and happy experience. This has been almost universal. Another thing that has not changed in the forty years between the births of Jerry Greenberg and Melissa Riggio is the sadness, depression, and feelings of 'why me?' that are noted above. There are also similarities that one might not expect to be there, for example, the fact that in the 1980's the Riggio's young pediatrician also used the antiquated and stigmatizing term 'Mongolism' to describe their daughter's condition. In comparing these narratives I am not trying to say that there are not parents today who experience very intense reactions to the birth of a child with disabilities, as did Betty Pendler when Lisa was born. Nor am I implying that there are no longer places and sub-cultures in the United States that are particularly unaccepting of children with disabilities.

What is glaringly different in the young parent versus older parent narratives is the current availability of information, diagnostic services, early intervention services, parent support groups and inclusive educational services that were entirely absent, indeed not even in the imagination of the most forward thinking parents and professionals, when Jerry Greenberg was born. In addition, the mainstream societal attitudes and stigma related to disability have so changed since Jerry's birth that neither Steve nor Laura considered these a major problem. This clearly was not so for the older parents and their children. Ann Greenberg recalled a conversation with Jerry Weingold's wife back in the late 1940's in which Mrs. Weingold told her that she always placed her "Mongoloid" son Johnny face down in the carriage when they went outside, and how 'lucky' Ann was that Jerry was a pretty baby. This is precisely the kind of acute stigma that was described in an article in the October, 1943 edition of **Parent's Magazine** (the year of Jerry Greenberg's and Johnny Weingold's birth) written by "a Mother Who Wishes To Be Anonymous." She stated, "…we know that many parents must choose between not taking a child out with them and braving the curious, pitying stares of the passers-by." [end note 2] These kinds of references are myriad in magazine articles of this era. Also, as part of this history the author interviewed residents of AHRC's 30th Street individualized residential alternative (IRA). Many of these residents, in their 60's and 70's, were the sons and daughters of founding parents. They clearly recalled when they were younger that many kids with mental retardation were "hidden away in the closet." Gilda Lindenblatt described in detail how kids would make fun of her and how she "did not like that one bit," especially when they did it to her in front of her mother. I asked the residents whether things today are still the same as it was for them and they collectively answered with a resounding "no!" Of course children and adults still make fun of persons with disabilities, but perhaps less so than when Gilda grew up. And more teachers and parents today are likely to correct children who engage in such behaviors.

It is often said that "the more things change, the more they remain the same." Yet, in the field of human services for people with mental retardation there have been such sweeping changes over the past fifty years one cannot escape the conclusion that younger parents today are in a qualitatively different position than their predecessors (this will be discussed below in Chapter 7). In fact, the rapidity of change in the disability field led Michael Goldfarb, the current Executive Director of AHRC, to recently remark, "I'd much rather have my kid in our programs now than when I first came here [1975]." This comment, I think, points out how quickly services for people with disabilities have recently increased in quality and in quantity. And, despite the fact that today services for persons with disabilities face a new era of social and fiscal conservatism with respect to matters of disability, one cannot help but be impressed by the dissimilarities between the America of the 1940's in which the Greenbergs cared for Jerry, and the America of the late 1980's in which the Riggios care for Melissa.

The next part of this document examines the role of parent groups, particularly the leadership role of AHRC, in producing these changes. The centrality of parents' contributions to the field of mental retardation is something that was a discovery of this research. Before interviewing the people involved and reading the historical materials, I could not have with warrant and sincerity written the following: In the United States, the history of community-based services for persons with mental retardation is the history of the parents group movement, and the history of the parents group movement, as a matter of historical record, can be traced largely to the development and contributions of the most influential parent group of its era, AHRC.

CHAPTER 3 - "AND NOW LET'S BUILD A BETTER WORLD": THE FORMATION OF AHRC

> "Our conversation was only about retarded children." Ann Greenberg, interview in 1998

In an untitled document written to Nat Feder, the President of AHRC in 1950, Ann Greenberg wrote the most detailed available history of the very early days of AHRC before its incorporation. The story appears in more abbreviated form in newspaper articles, in Herbert Lerner's history of the state association written in 1972, and several AHRC publications, but without the detail of this account.

As described above, Ann found out her son Jerry was retarded when he was 9 months old. She knew one other mother who had a retarded child during this period of Jerry's life. When Jerry was about four she met yet another mother with a retarded child, Mrs. Hunink, whose child was "Mongoloid." Ann discovered that there were no services for her son, she visited schools and didn't like what she saw. Jerry was not eligible for CRMD classes until age 7, if he met the criteria when he turned that age. Ann describes her position at that time,

> "From the time Jerry was small I had been writing letters, calling agencies, writing newspapers, radio stations, anyone I could think of, hoping somewhere someone would remember that these children needed something. Everyone answered, gave me encouragement, admitted they couldn't help and sympathized. I wanted help in finding other parents of retarded children. I wanted help in starting a school which we needed and which we couldn't get. I was turned down by everyone... I also made many telephone calls. I just went through the phone book. These agencies found out there was a problem because I brought it to their attention." [this shows

> many of the characteristics of the Parents' Movement-- tenacity, energy, need to make public and government aware of the MR issue]

Ann tried to send Jerry to a school in Connecticut when he was 4 but it did not work out. He missed his family too much and returned home after a few days. At the end of 1947, Ann found an in-home teacher for Jerry, Mr. Stanley Levin, who was to play a role in the early development of AHRC. About this time Ann made her first positive contact with the Bureau for Children with Retarded Mental Development (BCRMD) in the Board of Education, a Mr. Chris de Prospo. He tried to help Ann and the other parents she knew by connecting them with other parents of retarded children.

In the summer of 1948, when Jerry was not yet five, Ann decided to place an ad in the newspaper. In her words. "I felt it couldn't hurt." She had actually been mentioned in the paper before this, in a column by Dorothy Norman in the **New York Post**, and also on radio, on WMCA on a program called "Something Ought to Be Done" sponsored by Sachs Furniture. The program was aired on Sunday afternoon in the summer and Ann did not get any responses.

> "I got impatient and decided to put the ad in the **Post** right away. It appeared July 7, 8, and 9, 1948...It read something like this: "To parents of Retarded Children 4 to 8, Are You Interested in Helping to Start a Nursery School for Your Children? contact ...etc." I met the following parents from that ad- Pearl and Julie Schwartz, Rebecca Noble, Margaret Reiss, Rose Hurwitz and Mrs. Kanner...and of course Mrs. Lifschitz, Mrs. Hunink and myself. So we were nine people immediately."

At this time the parents, mostly mothers with fathers playing ancillary roles, began to do "a lot of running around...looking for other parents. A meeting was held. One of the members of the original group was unable to care for her son and had been forced to place him in Wassaic. Three new parents who had children in Wassaic joined them at that next meeting, but they never became active in the formation of AHRC.

Nothing happened for the next several months. The next break came when one of Ann's letters to the National Council for Jewish Women had eventually been directed to a Mrs. Ann Glatzer, a teacher at the Child Development Clinic in Brooklyn and associate of the then famous psychologist Dr. Helen Thompson. The parents visited Mrs. Glatzer in her home, and she volunteered to teach children in her home, which never came to pass. But what was important about the contact was that Mrs. Glatzer connected Ann's group with other parents she knew, adding significantly to their number. It was at this point that Ann decided to tell Mr. Levin, her son's in-home teacher, what she and her friends were trying to do. Levin was extremely supportive and urged them to continue on and to form a parent group. He was the person who told Ann about the Welfare League for Retarded Children, the parent group for children who had been placed at Letchworth Village. The Welfare League was an older organization but its concerns were different than those of Ann and her friends, whose children were "community children." It is interesting that Ann notes to herself, in 1950, that her perception of the Welfare League's parents as requiring something different was "...not entirely right but I did not know it at the time." [end note 3]

They held a meeting in the Fall of 1948 that Mr. Levin attended and at that meeting a formal decision to start a parents group was made. It was also resolved that ads would be placed in newspapers to find more parents. They set a next meeting date of December 10, in Mrs. Noble's home. Then six or seven of the parents recommended by Glatzer contacted Ann. An ad placed in the Post yielded ten more names. By December 10, Ann had a list of twenty parents and Mr Levin invited additional parents. They all showed up. Ann wrote, "We filled up her living room and some of us volunteered to be officers and we had an organization on the way."

Ann then wrote the **Post** again, this time telling them of the history and of having formed a parents' organization. At the same time Mrs. Noble wrote to Joseph Kahn, a reporter who had done a story about "our forgotten children." Her letter was answered by him and he wanted to meet the parents. An interview was conducted at Mrs. Noble's home to which Ann had come specifically armed with documentation of the lack of services for their children, thereby transforming a simple human-interest story into something more. She wrote, "We had a very interesting interview with him and he took all my letters back to his office with him so that he could write up a proper story, and he did just that." This "wonderful story" appeared in the **Post** on December 20th. That evening the parents happened to gather at Minnie Schaeffer's house, planning their first big meeting and how to publicize it as much as possible. The story that Kahn wrote listed Mrs. Noble's telephone as the contact number. That turned out to be a lucky happenstance since on the evening of December 20 Mrs. Noble was ill and had been unable to attend the parents meeting. "...She [Mrs. Noble] spent the whole evening getting telephone calls from people who had read his story and then I really had a lot of names," said Ann, who called the interview and subsequent article by Joseph Kahn "a very lucky break" and "our biggest jump."

Two other parents joined them that evening of December 20, Ida Rappaport and Ann Millstein. These parents had children in classes for children with retarded mental development (CRMD classes) at the time and they were later to split from AHRC to form the Association for Children with Retarded Mental Development (ACRMD), an organization of parents of children who were eligible for CRMD classes and considered "educable."

At the December 20th meeting it was decided to have the big meeting on January 14, 1949. Through Minnie Schaeffer, who took her son for therapy at the National Hospital for Speech Disorders, it was arranged that the parents could use the

Hospital's auditorium.

> "As you can see everything went very fast. I wrote to all the newspapers and several of them did put into the paper that parents of retarded children were planning a meeting in the National Hospital for Speech Disorders on Friday, January 14, and they all came. The auditorium was filled. People were standing in the hall. [a list of about 200 names of attendees is available]. Those of us who had spoken up to become officers ran the meeting. We gave out cards asking people to sign up. We told them everything we could. We set dues at $5. Many people paid right there. That helped get letterhead with my name as the office and my address to contact, and that's how we started...Incidentally, Jerry [Weingold] and the Hechts came to that meeting also. They were invited by Margaret Rosenberg who had met Jerry at Camp Arlen one day. She wrote me a letter telling me that she knew of a great guy who could help us and his name was Joseph T. Weingold. I sent him an invitation to the January meeting and he was there and he joined also."

The group incorporated formally on January 19,1949 and held its first elections. The first non-elected President, Julie Schwartz, had to leave town for employment reasons, and Jerry Weingold was elected the first President of AHRC, with Nat Feder, the person to whom Ann addressed her 1950 historical account, as first Vice-President. When it was later decided that AHRC needed an Executive Director, the job was given to Jerry Weingold and Feder became President. Several of the interviews I conducted, alluded to a power struggle between several members of the initial group of parents. As Jerry Weingold wrote in 1950, the very nature of parent groups is heterogeneous in every sense of that term. This was both a strength, in terms of the talents and skills brought to the group, and weakness, in terms of the problems inherent in melding different perspectives into one group. So, at the very inception of AHRC some differences may have surfaced. It was interesting that all persons involved who I interviewed mentioned this, but did not want to discuss it in detail and preferred to 'let sleeping dogs lie.'

Ann concludes her 1950 account with the following paragraph.

> "As you can see upon reading this, everything led to everything else. Everyone helped. Everyone tried but as Jerry used to say, "the time was just ripe!" It was after the war and we were all interested citizens. Incidentally, strangely enough many parents who joined us later and became very active all had children older than mine. Where were they all that time? Nobody knows. Nobody did anything. The time just came to do something and we did it."

What perhaps is missing but assumed in this 1950 account, surfaced in my 1998 interview with Ann, I include it in the epigram to this chapter. I had asked her whether the parents ever talked about the War when they got together? Her answer was somewhat sharp, "Our conversation was only about retarded children." The parents of these early years were committed to improving things for their children in an almost fanatical way. Jack Gorelick, a currently retired AHRC professional of many decades, recalls the post World War II period in a recent interview.

> "Part of my thesis is that the success of the parents movement has to do with the events of World War II. You know if you look at who was involved...You know almost every father, although fathers tended to be somewhat less involved, was a veteran. And you have these things that happened during the War. You have the Holocaust, people away for a long time in the service. And when the GI's came out, **they were not going to take shit from anybody**." (with emphasis).

The parents who formed AHRC in 1949 were committed to their mission in a passionate way. Jack Gorelick is probably exactly right in his analysis, that post-World War II America was such a society that a parents' movement could take form. Jack called the parents' movement "a ground swell...a popular movement...it's almost like spontaneous combustion. The time comes, and it's going to happen." Many of the parents interviewed had the same sentiments, accounting for the title to this chapter and monograph, "And now let's build a better world," a quote from Ann Greenberg in her 1998 interview. Founding parents, certainly the active parents, lived, breathed and ate mental retardation. They would have meetings over supper and cook in the homes where they gathered. They became a kind of extended family, and a committed family. In these early years many interviewees recalled the "warmth and committedness" that characterized their relationships.

Jack Gorelick and I also discussed the high preponderance of names of Jewish origin on the list of 200 persons who attended the January 14 meeting. In fact over the years many have thought of AHRC as a primarily Jewish organization. At the beginning this concentration of Jews can be explained by the fact that there were many Jews in New York at that time, that many of those Jews had socialist and even communist philosophies and tended to be politically outspoken union people. These factors may have played a role in the initial response to the advertisement for the January 14 meeting and in AHRC's early growth. But it is also true that AHRC quickly grew into an organization whose members' ethnic and religious identification reflected the diversity of New York City, even though its reputation as a 'Jewish organization' continued in some circles, and may have played a role in its development.

A final note on the bottom of the page of Ann's memo to Feder typed with a different typewriter, as if an afterthought and with a scrawled signature, "Ann Greenberg," dated simply, "1950." It reads, "Nat, you asked for the story and this is it. It is a good idea because years from now, nobody will remember."

CHAPTER 4 - "AN IDEA WHOSE TIME HAS COME": JOSEPH T. 'JERRY' WEINGOLD AND THE FIRST YEARS OF AHRC

> "As soon as I met him I realized he was somebody." - Ann Greenberg of Jerry Weingold

> "It would seem that the pent up energies of many years propel us forward and we move with a motion and volition beyond our control." - Joseph T. Weingold, 1950

There is a debate in history that goes something like this, "Do great men make history, or does history make great men?" It has always seemed to me that both propositions were true, and this can be very clearly seen in the case of Joseph T. 'Jerry' Weingold and the parents’ movement. He was the right man, at the right place, at the right time. Elected first President of AHRC and its first Executive Director, he later became Executive Director of the New York State Association. In these capacities he helped establish and set the direction in the field of mental retardation for the next several decades.

Virtually all the people I interviewed for this writing admired Jerry Weingold, even his critics. I have heard him described by a real variety of adjectives, depending upon to whom I was talking. Literally every interviewee acknowledged that Jerry Weingold was a brilliant man, effective politician and devoted parent to his son with Down syndrome, Johnny. Many felt that Weingold was one of the most influential figures in our country in both planning and instituting community-based care for persons with mental retardation.

This section of writing will attempt to communicate a sense of the person Jerry Weingold was and to describe the blueprint for community services for people with mental retardation that he wrote in 1950. Under his leadership AHRC thrived as an organization, as the review of AHRC's achievements in the first years of its existence will reveal.

Weingold the Man

The stories told about Jerry Weingold indicate that in many ways he was a romantic figure larger than life. One interviewee said, "Did you hear about Jerry Weingold being with MacArthur in Africa?" "No," I told him, "I haven't heard that one." He then went on to relate how Weingold had been ineligible for military service because of a birth defect to his right hand (another thing I had not heard, apparently he shook hands with his left hand). But, I was told he had somehow used his lawyer connections to get assigned to MacArthur, and MacArthur wanted to "put him in charge of the French Fleet." Jerry Weingold was a lawyer, and he was a large and sometimes intimidating man. He had also been a Rhodes scholar at Oxford, England and a champion swimmer. I was also informed that he could be extremely gracious (when he wanted to be) and thoroughly entertaining, and that he was adored by women. Although I never met Jerry Weingold, arriving back in the state after he had passed away, I can accept almost all these claims people made about him. But as to the status of the French Fleet story, I am not sure. Perhaps this is what happens when you take on heroic dimensions to those around you, as Weingold did for many parents at that time, who often looked to him for inspiration.

We have already heard about how Jerry Weingold was made aware of AHRC and came to the January 14, 1949 meeting. When he became involved with AHRC he was a successful lawyer in the fur business with his father and brother. As Ann's epigram to this chapter indicates at the outset Weingold was a leader. He so impressed the group of parents with his intelligence and organizational ability that they elected him President in February, 1949, through a write-in ballot, and made him Executive Director in March of 1950. One founding parent said of Weingold,

> "...And along came this idea that we needed an Executive Director and Jerry Weingold, if he were crafted by some genius could not have been more qualified. He was the most magnificent. I don't think his equal will be found anywhere, partly because I suppose inner motivation, but mostly because what was between his ears."

While there was heated debate about whether any parent should be paid to work for the cause, Jerry was clearly the right choice for Executive Director, and when it became obvious to all in the beginning of the next year that one was needed, he was appointed.

Before examining Weingold's 1950 formulation of his vision of services for children and adults with mental retardation in the State of New York, and the achievements of AHRC in the first years under his guidance, here are a few telling anecdotes about Jerry Weingold's character and his early leadership of AHRC. Jerry Weingold was a hero of sorts to many of the parents at the time. Gene Gramm had praise for Weingold in that he was,

> " ...a heroic mold for me because all my heroes had a sense of humor... Jerry's sense of humor...was a kind of black comedy...ironic humor. Somebody once approached him, a woman, and said, 'I don't want to sound like this is a competition or anything Jerry, but I notice that the parents of Down syndrome children are invariably brighter or more intellectual...' He benignly looked at her over his glasses and he said to her, 'Well..better luck next time.' "

Weingold's sense of humor was renowned, an ironic sense of humor that complimented his intellectual nature. It was a humor that was respected and shared by many of the other active parents. But it was his overall commitment, intelligence, and leadership that made the parents admire him.

Jerry Weingold was also described by everyone as politically astute and sometimes even Machiavellian. In order to achieve what the parents needed to achieve, his "curmudgeon-like" personality proved extremely useful. The following occurred in the mid 1950's when AHRC was pressing the state to start public school classes for children below the IQ of 50 and displays not only Weingold as political strategist, but also his relationship with the parents of AHRC. The Association was having trouble getting the Governor to support their position that there should be public education for these children.

> "I remember going up to Albany one time when we were having problems...And Jerry asked some parents to agree to send their severely retarded sons and daughters up by bus. I think there were two busses, about sixty to eighty people. He asked the parents to agree to leave their kids there if we didn't get anything from the Governor. And so we go up there and have our demonstration, and Jerry Weingold goes into the Governor's office...He was there a while..I don't know if the press covered this or not...But I do know that the idea was that if we don't get what we want, we're leaving the kids up there. You know...you take care of them. We can't...we've had it up to our ears and that's it. You take care of them. We're going to leave. The parents agreed to do it. We were going to do that.
>
> "So Jerry goes in to see the Governor and the Governor is begging for more time, saying, 'I'm doing what I am doing,' and begging for more time. And Jerry Weingold said, 'You know Mr. Governor,' whatever he called him, 'its always like this.' Then he said, "You are going to find out what it is like to take

> care of them because I want you to know that we are going to leave these kids here. And you know what? Most of them are not toilet trained and they are going to shit all over your floor.' And the Governor said to Jerry, 'Oh no Jerry, you wouldn't do that.' To which Weingold replied, "We're doing it, we're leaving, good-bye,' and he headed for the door. And on his way out the Governor was yelling, 'Jerry, Jerry, come back, come back.' (pauses with a smile on his face) And that is the way he got things done. Jerry was a direct action kind of guy...This is my proud possession [indicating a small statue that he is holding]. That says, 'Sue the bastards.' That was his...on his desk."

This anecdote is a revealing one. It shows what Jack calls a style of "direct action." Weingold, throughout his career was able to achieve, by a combination of political smarts and direct action, incredible changes in services for children with mental retardation. He knew what had to be done to achieve the parents' goals and was willing to do it. But the anecdote reveals indirectly another thing about Jerry Weingold, how much he was trusted by the parents at AHRC. How many parents of children with severe disabilities would trust an Executive Director of a parents association enough to walk out on his command and leave their children in the care of the Governor?

Weingold developed extraordinary contacts in State government, and also to some degree with national and international governments and professional associations. He also had good ties to the American Association on Mental Deficiency, particularly to Lloyd Yespen who had recently been president of that organization (1947-48) and who Weingold cites in the first edition of "**Our Children's Voice**" (March 18, 1949) as "...one of the most eminent authorities on mental deficiency...and one of the most stalwart champions of our cause." Through such contacts Weingold was very aware of trends and developments in the field.
He knew the value of networking and public exposure, as will be seen when we

review the achievements of AHRC in its first year. And, it is true that happenstance also played somewhat of a role in his success. His association with Bill Conklin, State Senator from Bay Ridge, Brooklyn, was well known. They were long-term friends and cooperated in the legislative efforts to secure services for retarded children. With Conklin, Weingold authored many pieces of legislation that were to become state law. But Weingold actually met Conklin by chance, as the following anecdote told by Jack Gorelick conveys.

> "You look at our OMRDD and you ask, who brought that about? You think legislation and again you know it was like a God send. Jerry Weingold and Billy Conklin... Bill Conklin on the train to Albany, you know, they're sitting next to each other...And one guy says, 'What do you do?" And the other says, 'Well, I'm with AHRC and have a Mongoloid son...Bill Conklin says, 'Well I have a Mongoloid son, too. And I was just elected State Senator from Bay Ridge...' These guys wrote all the legislation. Jerry wrote it, and Conklin got it passed." [end note 4]

While the anecdotes about Weingold could literally fill a volume, as could his writings and poetry, I leave the reader with a seemingly trite but ultimately important observation about Jerry Weingold. When AHRC was pioneering travel training for persons with moderate mental retardation, Jerry Weingold was one of the strongest proponents of the program, even though everyone knew that risks were involved. Early travel training was described to me by Devino Riondato, the first teacher to be hired by AHRC for its pilot special education classes. Because it had never been done before almost everyone involved had extreme apprehension. But Weingold realized and insisted that this program move forward because he realized the role independent travel would play in employment for the retarded. Despite his convictions and principled statements about travel training, he never allowed his son Johnny to engage in the program. Instead, Weingold would drive Johnny to the workshop each morning.

In a way this "inconsistency" in Weingold's words and actions point to the complexity and contradictions of this man. At heart, and virtually everyone I spoke to about Jerry Weingold had absolutely no doubt on this point, he was motivated by his love for his son, with whom he maintained an extremely close relationship throughout his life. He may have been overprotective at times, as many parents of children with disabilities are wont to be. But, he followed his own advice to the AHRC parents to keep "our faith in our children" as he wrote in an early edition of "**Our Children's Voice**." That, he knew, was what would keep him, and them, going in their struggle.

Laying Out The Blueprint

George Hirsch, a two time President of AHRC, recalls Jerry Weingold's efforts to formulate a general approach to the problem of mental retardation in the State,

> "We laid out a program, cradle to grave. I sat with Jerry Weingold and two other people and said, 'Let's find out what we need now and what we need later..."

Weingold actually consulted with many persons in building AHRC's plans to increase and improve community and institutional services for persons with mental retardation. As Mike Goldfarb pointed out in our interview, the actual implementation of this plan followed in large measure the maturation of the children of the founding parents. First were clinics, then classes, then workshops and so forth. The "proposed long-term program" was provided by Weingold in his in-house paper of May 17,1950 titled, 'The Formation of Parents' Groups and The Relation to The Overall Problem of Mental Retardation,' a version of which later was published in the **American Journal on Mental Deficiency(AJMD)** (January, 1952: 484-492).

The paper is for its time absolutely brilliant and prescient. While Weingold can not be said to have laid out the entire field of mental retardation as we know it today, for example, he does not discuss self-advocacy or the closing of institutions, the degree to which he describes the basic problems and solutions to the situation of families who have children with mental retardation is, again given the era of these remarks, uncanny.

It should be remembered that Weingold was in contact with Lloyd Yepsen, who was at the Vineland School Research Department at that time and who had just served a term as President of AAMD. Yepsen was himself a brilliant and compassionate man who worked with Weingold in helping him to formulate AHRC's plans. Weingold and his companions also had ties with Richard Hungerford, who was to serve as AAMD president from 1950-51 and whose October, 1949 article in the **AJMD** 'Minimums of a State Program' was actually adopted "in its entirety" by AHRC in its long range objectives. Dr. Helen Thompson and Dr. Clemens Benda also probably had some input into Weingold's thinking. In actuality, many of the features of Weingold's blueprint reflect ideas that had been adopted by professionals in the AAMD as early as 1940. In a mimeo document titled, "Practical State Program for Care of the Mentally Deficient" adopted 5-22-40 by the American Association on Mental Deficiency, we find six major areas explicated. [end note 5] The early AHRC blueprint for the overall development of services for people with mental retardation would appear to be informed by this earlier AAMD document, and Hungerford's article.

But Weingold's plan was not just a restatement of the professional plan, it was a "parentalized" version of it, that specifically identified and linked the parents' interests with many of the above provisions. The AAMD suggestions are very sketchy and general, merely a kind of outline without content. Weingold's paper is an eighteen-page exposition of the parent movement and its relationship to the development of services necessary to address "the overall problem of mental retardation." It showed incredible self- and historical awareness, as well as demonstrated why persons who knew Jerry Weingold were so impressed with what was "between his ears."

Weingold began with an analysis of the parent movement, itself impressive in that AHRC was only one year old when the paper was written. In that part of the paper he emphasized how the parent movement was slow to start but quick to grow. He described some of the problems parents groups faced, and the difference between AHRC and the institutional-based groups. He also devoted considerable space to the problems inherent in parent groups, such as their heterogeneity and lack of organizational experience.

As we will see shortly, at this time AHRC had already made an impact in the City and State and had grown incredibly. In 1949 when it was incorporated the organization had a mailing list of about 200. In 1950 when Weingold wrote this paper, the mailing list was over 10,000 and included national and international entrees. Part of the early success of AHRC was a result of Weingold's strategy to "enlist some of our critics to help us." The organization had begun a steady stream of correspondence to governmental and professional groups. Some of these were put on an Advisory Board in order to incorporate new ideas and to encourage cooperation between parents and professionals. This is probably another reason why the plan announced in this paper reflects both professional and parent beliefs.

The blueprint began with a plea for educational services for children with mental retardation.

> "It is our contention that it is the function of the community to provide training

> and educational facilities, not only for those considered eligible to the special classes in the school system (and many communities do not even have these classes) but also for those considered to be the 'institutional type,' whatever that means, on the basis of a certain I.Q. level...there is still too much reliance placed on I.Q. and similar tests all geared to the normal...Even if these children can only receive training in self-help and social adjustment, this should be a function of public education." (pps. 8-9)

This text could have been written today. This is even more true when one considers that immediately before this paragraph appears Weingold calls for early education for retarded children, and as one can see from the above quote, for all retarded children, not only 'educable' ones.

The next part of the blueprint called for recreational, athletic and after school activities for children with retardation. Asserting that adolescents with retardation "are too part of the youth of this country," he described the vocational training and active social life that is required for these youngsters. He was specific in his view that employment should include sheltered workshops and ordinary employment. The AHRC plan in 1950 was primarily concerned with children and young adults, although it did call attention to the plight of retarded persons more than sixteen years old and the need for services for them.

In addition to these kinds of community-based services Weingold called for, and specifically described AHRC's attempts at establishing clinics for diagnosis, remediation, pre-schools and kindergartens for the youngest children.

While the program did include recognition that conditions in the state schools needed to be improved, Weingold was also clear about his preference for community-based services.

> "It is our position, and we are joined by the progressive men directing State Schools, that a community program should be set up that obviates the necessity for institutionalization except in the cases of the most severely retarded." (9)

One finds a discussion of the need for guardianship (Weingold eventually writes this legislation for the state), for research into the causes and prevention of mental retardation (he supported the foundation of the Institute for Basic Research on Staten Island), and adequate and realistic teacher preparation. He also mentioned the importance of parent training and support. He stressed the role that AHRC would have, as opposed to previous parent groups, in creating new legislation and implementing existing law. And Weingold described the importance of educating the public about the issues.

> "A gigantic campaign of education [is needed]. Society tends to reject and shun what it does not understand. The misconceptions about mental retardation range from the ridiculous to the dangerous." (11-12)

There was a very aggressive public awareness campaign launched by AHRC at that time that included letter writing, television and radio appearances, newspaper coverage and intensive networking. (see below discussion of the **New York Times** advertisement)

While the overall plan suggested in Weingold's paper was not primarily geared towards adults or older persons with mental retardation, what it does lay out in a comprehensive way, is amazingly consistent with our current system of care. This is especially impressive given the conception of disability that was dominant in the field at that time. On the other hand, in this plan and other places he mentioned the need for psychotherapy for parents with retarded children, putting a slightly psychiatric spin on their situation. In many ways he, and the paper, evidenced a kind of awareness of mental retardation that is quite different from our own. But this only makes the relative comprehensiveness and correctness of his thinking about the overall future development of the field even more remarkable.

A "Nomenclature of Despair"

We have already encountered the parents' experience of the nomenclature of mental deficiency. Weingold's position on nomenclature in his paper seemed consistent with this experience.

> "I should like to point out here that this would be an excellent time for the professional group in the field, the AAMD, to reexamine the semantics of mental retardation. We feel that we have been and are hampered in our work by the terms so long used to describe various forms and levels of retardation. Of course, Parents' Groups must be realistic. They cannot afford to build false hope, but neither should they have to face a world with a nomenclature of despair. The terms used today are those of defeatism. Idiot, imbecile, moron, are no longer terms of art: they have been preempted by literature and cheap vaudeville. Their connotations are those arising from the novel and the low comedian. It is extremely unrealistic to ask Parents' Groups to do a selling job with such unpalatable labels for wares which deserve better." (14-15)

This concern with changing the terminology of professionals was a specific focus of the founding parents. Another parent stated in our interview,

> "They used to be called 'Mongoloid Idiots.' That was the term for them. To me, that was one of the greatest triumphs, along with the tangible edifices,

> nurseries, sheltered workshops...was getting the terminology changed. We lambasted these physicians and we got them to change...That was the beginning of a new terminology, which was not just more humane but so much more accurate and analytical."

Later in the interview this parent emphasized that it was not just the stigma of the terms and the psychology of their effect on parents that was at issue. It was also the fact that the mission, the parents' goals for their children, were seriously negatively effected by the terminology of despair. The parents found it difficult to portray a hopeful image about the development of services to "idiots" and "imbeciles."

Ann Greenberg also said that it was one of the great victories of the parents groups to have influenced the professionals to change the nomenclature from that of mental deficiency to the current one of mental retardation. Tracing the historical trail of the adoption of the term 'mental retardation' I believe that there is warrant for her and other parents' assertion, although AHRC was not the only group that was involved. Parents began being active in AAMD in the early 1950's when discussions about a terminology change were just beginning. In 1952, for example, Elizabeth Boggs, a New Jersey parent who was eventually to become a powerful national figure in the field through NARC, attended a meeting of the AAMD Nomenclature Committee. Not only was the terminology of mental retardation advanced by this committee, its conception of mental retardation was remarkably contemporary. AAMD officially changed its terminology to that of mental retardation in 1959. While one cannot attribute this entirely to the role of parents and parent groups at the time, the pressure they applied on professional groups undoubtedly played a great factor in hastening the change. [end note 6]

The effort and vigor with which parents lambasted physicians probably accounts for why today many of them are still committed to the term "mental retardation" and have resisted recent efforts to change it. While space does not allow for a full discussion of the issue, the reader is asked to permit a small digression on nomenclature in our field today. From the perspective of self-advocacy organizations today the term "mental retardation" has become objectionable. Many have pressured groups such as Association for Retarded Children or Citizens to remove the word "retarded" from their name. Thus, some years ago the NARC became known as "the ARC." Other organizations have followed suit given the pressures from the self-advocates. It is ironic but understandable that this is occurring today. The people pushing for the current change of terminology to a more humane and accurate one are the children of the founding parents. Unfortunately, as is the way of all terms, the social conditions surrounding words ultimately gives them their real meaning. And the social conditions for persons with mental retardation in the 1950's and 1960's were still awful. They were stigmatized, exempted from regular education and given 'special classes.' And some were incarcerated in institutions experimented upon and abused because they were "mentally retarded." Obviously this was not the intention of the parents in initially pushing for this term. They had no idea that, eventually, it would take on the "baggage of the era." But it does seem sensible, given this history, that self-advocates who grew up in this era would have come to dislike the term and want a new one. [end note 7]

The view professed by Mike Goldfarb is that language itself has a limited power to effect the social processes through which people are devalued and oppressed. Indeed, positive language used in such situations can be euphemistic and misleading, actually enhancing devaluation. However, it is also true that language is not unimportant, and it does influence our perception of people-- that is exactly why the founding parents objected to the old nomenclature. With limited time and resources, if one needs to make a choice, it is probably better to worry more about changing the social processes by which persons are demeaned than the language used in doing so. And certainly, as Goldfarb points out, "it is simple minded to think that calling people who are socially demeaned and diminished by a different name is going to have them cease to be diminished or demeaned."

When I wrote that in a very real way the history of the mental retardation movement was the history of the parent movement it was intended in this literal way. Parents actually were largely responsible for hastening the change to a less stigmatizing terminology for their children. Furthermore, as Jack Gorelick put it, "all the good things happened because of the parents and in spite of the professionals. We professionals are the ones who brought them Willowbrook. [elbows my side with a sardonic grin] We are the ones who exempted their children." Perhaps this is a bit one-sided; but just a bit.

Accomplishments of the First Years

In a mimeographed document (dated 1950 probably written in January or early February), AHRC reviewed its rapid development. The following are some excerpts from that document.

> "As AHRC gained in publicity in newspapers, on the radio, in Parents Magazine, etc., parents by the hundreds flocked to parent education meetings. These monthly meetings were addressed by Mr. Stanley Levin, Dr. Lloyd Yepsen, Dr. Helen Thompson, Dr. Arthur Foxe, Mrs. Pearl S. Buck, Dr Arthur Whitney, and Dr. Clemens E. Benda. Several of those mentioned were also asked to serve on AHRC's Advisory Board, which also included the actor Drew Pearson.
>
> "AHRC published a pamphlet which details some of its long range objectives...

> "In autumn of 1949 AHRC representatives met with Dr. Frederick MacCurdy, Commissioner of the New York State Department of Mental Hygiene, Dr. Harry C. Storrs, Senior Director of Letchworth Village Training School, and Mrs. Crystal Potter, Deputy Commissioner of Welfare in the City of New York. The recommendations made at that conference are still under consideration by New York State authorities. Governor Dewey paid public tribute to the Association in his remarks at the ceremony. At the luncheon he promised to meet with members of the Association in the early part of 1950
>
> "The Association also publishes a monthly newspaper called "**Our Children's Voice**" for which there is no subscription charge at this time."

The document also indicates that AHRC had met with officials in the Board of Education and in social service agencies in New York City to begin discussing plans for **pilot** classes and clinics. Indeed, this was AHRC's plan from the outset to set up pilot programs in New York City and then around the state. These pilots would demonstrate the feasibility of various ideas but in no way would they imply that it was not the duty of the State to provide these kinds of programs, clinics or classes. This is why in the early years almost all programs, except for parent education, were called by the term 'pilots.' It was announced in this early 1950 document that "AHRC is negotiating with a charitable organization in Brooklyn toward the establishment of the first clinic, and an announcement should be forthcoming."

In addition to the achievements listed in this document, Ann Greenberg's typed "A.H.R.C. New York City Chapter - Chronology," provides information about the first year's activities. These activities included the opening of an office at 1133 Broadway, the inauguration of a $100,000 fund drive, the government granting AHRC tax exemption, the winning of official endorsement of Emmanuel Cellar

(Congressman from Brooklyn) and John Cashmore (Brooklyn Borough President) and in December of 1949, the Bronx House offering to AHRC of classrooms to be used five mornings a week.

By the beginning of 1950 AHRC had grown to be an organization of about 1,000 persons, 700 of whom were parents, the remainder interested professionals and relatives. Nearly $14,000 of the $100,000 drive had been collected and Chapters had been started in Westchester County, Sullivan County and Long Island. [end note 8] The parents were involved in networking activities, especially in finding other parents of mentally retarded children. In 1949 and 1950, they attended professional meetings such as the AAMD, served on The Committee of One Hundred in New York State, and went to the White House Conference on Children and Youth and served on the Project 4 (problems of the mentally retarded). AHRC actively engaged the other parent groups in the state for the purpose of coordinating efforts.

The first clinic was opened in February of 1950, just one year after AHRC's incorporation, at Flower Fifth Avenue Hospital with Dr. Lawrence B. Slobody as Director, and with the support of Dr. Margaret Giannini. The first formal parent education courses began in March, and in April, as an adjunct to Flower-Fifth Avenue Clinic, the Lena Invalid Society donated $6,000 to allow for the opening of a speech clinic.

The First Annual Dinner of AHRC was held on May 20, 1950 at the Astor Hotel. It marked the tradition of annual dinners and awards that would come to characterize AHRC, and still does. The public relations value of these ceremonial gatherings was clearly appreciated by the AHRC leadership from the outset. Huge efforts were made to have this first Annual Dinner be impressive in quality and scale, even though the organization was still relatively small and poor. In the dinner program, photos and statements from Governor Dewey, Pearl Buck, Drew Pearson, Cong.

Emmanuel Cellar, and Richard Hungerford appear. Jack Max, the Chairman of the Dinner Committee, makes special mention of the contributions of City Coordinator Albert Leavitt, who "gave so unstintingly of his valued time and talents" even though not a parent. Max specifically mentions the members who "worked evenings and weekends...and ran their household by remote control...these men and women taught me what the words 'unselfish devotion' mean." The scale, political maneuvering and public imaging involved in the First Annual Dinner would have been impressive for any organization, let alone one staffed by volunteers, with a professional staff of one and that had been in existence a little over one year!

As was mentioned, public awareness of AHRC was a critical concern of the founding parents. Ann's chronology of early achievements mentions the advertisement taken by AHRC in the **New York Times** in December of 1950. As part of the public education campaign, the advertisement used pity and compassion to raise money for the organization by putting the picture of a physically challenged child coupled with the caption "This is a picture of a crippled child." Just below the picture a further statement was printed indicating that you may not be able to see his disability because "it is his little brain that is crippled." This was an important ad in the history of AHRC, an expensive one that was paid for by having many small donating organizations whose names appeared in a list to the right of the advertisement. Through this ad, AHRC became known in New York, around the country, and even the world. The ad was both a device for public education about children with mental handicaps, and a fund-raising and membership tool. It was highly successful on all accounts. Not only was the ad influential in its era, for example, after reading it President Eisenhower asked that the author should "write the proclamation I sign..." for National Retarded Children's Week. Years later AHRC was still including it in their information package sent to prospective members.

Understanding the power of media, what it could do for the parents' cause, and the incredible efforts in this area undertaken by the parents in the first year of AHRC's existence, are two reasons cited by Alfred Katz in 1957 in explaining the success of AHRC. The other reason was the incredible persistence of parents in networking with other parents of children with mental retardation and getting them involved in the cause. The degree of networking and public education is reflected perhaps most impressively by the growth of the mailing list from 200 to 10,000 in the first year.

Ancillary to these New York City and State focused activities, Weingold was also instrumental in initiating and establishing a national parents' group. He had proposed such an idea in a paper, and certainly to other parents around the country before attending the AAMD meeting in Twin Cities, Minnesota at the end of September/beginning of October, 1950. In Lerner's history of AHRC and elsewhere, Weingold is given credit for having proposed the idea to other parents around the country. These parents met at the AAMD meeting and drafted a document titled, "Recommendations of The Steering Committee of Parents of Retarded Children Groups With Regard to the Formation of A National Organization of such Groups." It was a manifesto-type statement with enumerated goals and a call for participation. It was signed by five parents: Allen Sampson of the Washington group, Irving Bieber from Los Angeles, Eleanor Hayes from Massachusetts, Alfred Kamm of Dayton Ohio, and Joseph T. Weingold of AHRC New York City.

In the January-February, 1951 edition of **Our Children's Voice**, AHRC's accomplishments for the previous year are described: two diagnostic clinics, a speech clinic, play therapy groups, a social activities program for children, a vocational training program, summer camp scholarships, parent education courses, and public enlightenment. Weingold had also contacted the Division of Vocational Rehabilitation and Goodwill Industries about beginning job placements for mentally retarded youth and adults. Also by this time AHRC was leading a movement to create a coordinating body or council that would represent these groups in a united front to the legislature. Finally, in February of 1951, AHRC was formally admitted to the Greater New York Fund, entitling it to receive contributions. Indeed, AHRC was denied membership to the Fund in early 1950 on the basis that it had no Executive Director, which is partially what motivated the hiring of Weingold. Normally the guidelines said that an organization had to exist for three years to be eligible for funds. Weingold secured membership in two years.

The reader should not come away with the impression that AHRC was only victorious in its first years. Politically changing the system in New York State was going to be much more complicated than the initial endorsements by political figures would have indicated. For example, Weingold and other parents wanted very much for the State to appoint a special committee to consider the overall problem of mental retardation in the state. Governor Dewey, whose public posture toward AHRC was highly supportive, essentially killed in committee the bill introduced by Senator Earle Brydges and Assemblyman Sam Roman. **Our Children's Voice** (Vol.III, March-April, 1951: p.2) devoted several pages in its history of AHRC documenting the tactics used by the Association and its advisers, Chris DeProspo and Richard Hungerford, to try and get the legislation passed. The events and meetings cover three pages, single-spaced. The Association failed in its first attempt-- a disappointing failure but one not to set them back! In an editorial in that same edition of **Our Children's Voice** an editorial credited to the Board, was titled "The Resolution That Died of Kindness," in which it was claimed that AHRC suffered defeat on this issue because its approach was too soft, it did not rally public opinion and it was too diplomatic. It called for building a "fighting spirit" while being careful not to "make enemies of the powers that be." But it was also vowed that no such resolution would ever die again as a result of insufficient pressure or over politeness.

The saga of this legislation does not end here. Only a few months after it was killed in committee, it was reintroduced by the same state legislators, this time with the benefit of additional support within government and in the community (the legislation was the focus of AHRC's first statewide conference). While the legislation again failed, Governor Dewey, in a compromise proposal, authorized a survey of the "extent and care of mental deficiency" and $25,000 for this purpose. AHRC wanted a Legislative Committee to be appointed and wanted parent representation on the study. Dewey's compromise was intra departmental, without parent representatives, and with limited funds. Nonetheless, it was regarded as a victory by Weingold and the other parents, even though it was a compromise. Lerner comments, "It appears that AHRC had mustered its forces well. It worked together with the parent groups for institutionalized retardates...on influencing the governmental department first...The result was a compromise that authorized serious study of the problems of retardation...By hailing it as a victory, the Association had apparently begun to accept the compromising nature of the American political system."(64). Later in 1952 Weingold was appointed to the Advisory Committee of the study that was to be done by the Department of Mental Hygiene. This actually gave parents some say in the decision-making process surrounding that study.

Despite this development and the increased awareness of parents of retarded children by legislators, AHRC continued to experience defeat in terms of its early legislative proposals. One of its earliest programmatic focuses was on building services in the community for children with I.Q.s below 50. Initial attempts were made to influence legislators to examine this problem. Again the parents experienced considerable political indifference and resistance. In 1953, an omnibus bill to the Legislature proposed by Assemblyman Roman and Senator Brydges was killed in the Finance Committee of the Senate and Ways and Means Committee of the Assembly. Weingold called for additional emotional pressure to make the legislators see their responsibility to children with retardation (**Our Children's**

Voice, March, 1953). The response of AHRC was to present the same legislative proposal the next year, with the additional proviso that classes for trainable should also be started in institutions and state schools (thus involving the State Department of Education in institutional services), and also a phasing in period for classes for this population. Standards were proposed for entry into these classes. The proposal had even broader backing than the original one, including the support of the State Federation of Women's Clubs and the State Teachers Association.

In response to the increased political pressure on March 11, 1954 Governor Dewey recommended an allocation of $50,000 for experimental classes for severely retarded children to be set up-- five in the city, two in up state and five in state schools. This proposal passed the Legislature unanimously. The same type of pattern can be seen here as with earlier AHRC efforts, for example, the issue of the special study commission on the problem of mental retardation in the state. Initial resistance and failure is met with insistence, perseverance, increased networking, and public opinion mustering. Eventually the parents would achieve some form of a 'victory.'

Looking back at the first years of AHRC under the guidance of Jerry Weingold, one cannot help but be overwhelmed at the amount of effort these parents put forth as well as their relative success. At the same time, I do not want to give the false impression that things came easily to them, or that they did not experience many defeats along the way. The brief vignettes about initial attempts to influence government and service systems were included to illustrate this. In fact, success did not come easily to the parents during these years. The political climate in America was not ripe yet for their message. Throughout the 1950's AHRC grew at a relatively slow pace. Its primary value during this period was in creating public awareness of the overall problems of people with mental retardation, effecting legislation, and demonstrating the feasibility of AHRC's long range proposals through the establishment of pilot classes, workshops and educational programs.

AHRC initiated thinking about the overall problem of mental retardation on the City, State and national level. Among parent associations AHRC was clearly the leading association of this era. It gave the parent movement both vision and, as Jim Murphy (President of AHRC, 1974-77) put it, "it created scale." Of course not all the changes in the State or City at the time are strictly the result of parent groups' political pressure. Other bodies and professional groups also contributed in their own right. But, there can be no doubt about who was in the lead, and that was the parents.

This then brings us to Weingold's often used quote in documents of this era, paraphrased in the title to this chapter, "An Idea Whose Time Has Come." The quote is from the French Enlightenment philosopher, Voltaire, and reads, "There is only one thing greater than all the armies of the world, that is an idea whose time has come." This statement summarizes the spirit of the founding parents of AHRC more than any other, which is probably why Weingold used it often to close his documents and speeches. He and the other parents felt they were involved in a righteous cause. They were in a battle for the lives of their children. Often he would joke and indicate his optimism about their ultimate victory when other parents expressed doubt. He would remind them that "our cause is just." The way he saw it, the parents were going to win; they had to. They would do whatever it took. And they did.

CHAPTER 5- GROWING UP IN THE 1950'S AND 1960'S

> "A civilization is measured by the kindness and justice of its treatment of the helpless." -- Pearl S. Buck, 1950

If the 1940's mark the birth of AHRC, then the 1950's and 1960's represents its childhood and adolescence. The organization's growth participated in the general changes with respect to people with disabilities at this time, both within the United States and internationally.

It was during the late 1950's that Denmark adopted its laws on disability based upon the **concept of normalization**, that is, the idea that people with disabilities should be able to live a life as close to the normal as possible. At the same time Denmark and other Scandinavian countries began what was to be known in the United States as the **Deinstitutionalization** movement. The Danish parents, working closely with the Ministry of Social Services' Neils Eric Bank-Mikkelsen, were instrumental in pushing these agendas before the public. Americans were beginning to be aware of these changes in the welfare states in Europe and were starting to bring some of these ideas into the United States, although their full expression and influence was not to be seen for another decade. Nevertheless, because of the efforts of parents themselves, international changes in human rights, and other economic and social factors, the 1950's began to see a positive movement in the lives of persons with mental retardation.

The Middle and Late 1950's

As stated in the previous chapter the parents in AHRC during the late fifties were occupied with issues related to public awareness and program development. The enlisting of entertainment personalities for the cause was impressive. As described in **Our Children's Voice**, even by 1953 such names as Morey Amsterdam, Kitty Kelley, Milton Berle, Sarah Vaughn, Jack Barry, Walter Abel, Pearl Buck, and Jan Murray had already been involved in AHRC fund raising. There had been several coast-to-coast broadcasts on NBC's show "**It's A Problem**" and Alex Russotto, then President, had appeared on Barbara Wells' television program. Bobby Breen was also doing "his punchy pitches" (i.e., fund-raising appeals) on radio. AHRC experienced fund-raising success and increased public awareness of their children's situation through these and other efforts. Public education by other organizations for children with other disabilities also began to take on more public importance at this time, and enjoyed increased media exposure. AHRC and parent groups of that era were part of a more general awakening to the need for public education on issues related to children=s disabilities through the media

About this time, the organized media itself began playing a role. In 1956, Sam Cook Diggs produced "**The Wassaic Story**," that was telecast on CBS-TV's "**Eye on New York**," and later on CBS-TV's network, coast to coast. It won the Albert Lasker Award for TV reporting on medical/public health issues. In his address to AHRC's Annual Dinner at which he was given an award, he pledged broadcasters "wholehearted support to the fight-- to solve the problems of mental retardation." A year later, in March of 1957, **Westinghouse Studio One** televised Abbey Mann's "**A Child Is Waiting**" on CBS network television, the first dramatic show on network TV to deal with the problem of mental retardation. This program had a great impact on public awareness at that time. It was praised by reviewers in the **New York Times** and elsewhere. AHRC presented an Award of Achievement to its producer, Herbert Brodkin, "for the intelligent and sensitive way the problem of mental retardation was presented to the American people. [end note 9]

Towards the end of the 1950's there was an expansion of legislative appropriations to human services on the state and federal level, and some of AHRC's involvement in legislative efforts were documented in the previous chapter. The trends in appropriations to this sector must have been obvious to AHRC in 1956, as their 7th Annual Dinner Awards to John Fogarty and Earl Brydges indicate. Twelve hundred persons were in attendance. Fogarty was the Congressman who, as Chairman of the House Appropriations Subcommittee on Labor, Health, Education and Welfare, was credited by AHRC for "outstanding contributions to the cause of mental retardation through courage in pioneering a broad program on a national level." **Our Children's Voice** (June-July, 1956). He created the first Congressional level panel on the topic and generally increased the appropriations to Health from $ 3.5 to 135 million in the ten years of his tenure as Subcommittee Chair. He also was credited with appropriating the first federal research grant in mental retardation, $750,000 in 1955. Brydges, as will be remembered from the previous chapter, was a State Senator who was Chairman of the Joint Legislative Committee on Mental Retardation and of the Senate Committee on Public Education. At the Dinner he was praised by the Association for "leadership to obtain services for the mentally retarded and help them achieve the dignity of individuals and citizens." Through the lobbying efforts of the parents associations on the national, state and local level, legislation and appropriations to help persons with mental retardation was slowly on the increase.

In accordance with the general direction of its long-range plan, AHRC participated in a moderate expansion of programs throughout the 1950's and 1960's. In 1953 AHRC opened its first workshop. Jerry Weingold was instrumental in pushing for vocational programs, including regular employment, and worked closely with Mary Switzer in Washington, D.C. on a national level demonstration program that was coordinated through her office. This was to mark the entry of AHRC into the employment sector, which was to become a major part of its program development efforts. Also in 1953, the Association opened its first experimental nursery for preschool children. Along with the parent education classes and clinics begun in

1950, the pilot classes for 'trainables' begun in 1951,[end note 10] and the social groups that were instituted in 1952 (the same year as the formation of the New York State Association for Retarded Children (NYSARC) with seven chapters), by the end of 1953 several of the basic elements of the long-range plan were being demonstrated.

The ensuing years saw the expansion of all services. The waiting list for clinics was 2500 by 1954, indicating the extreme degree of the need. Camp programs were expanded, even Camp Poynelle, where "the retarded and the normal share camp activities," were in place by 1954. In 1955, New York State issued a legislative declaration that "the responsibility for the education and training of retarded children rests upon the State and not solely on the parents." That same year AHRC received a grant under the Vocational Rehabilitation Act of 1954, further expanding their sheltered workshops. In 1956 there was a push to put into place recreation and social programs, such as after school programs, social programs for teenagers, and scouting programs. In 1957, social worker Meyer Schreiber began to counsel parents as part of the Association's parent education efforts. In 1957 Weingold proposed to the State that it build a Research Institute for Mental Retardation (an idea that later came to fruition with the opening of the New York State Institute for Basic Research in Mental Retardation on Staten Island). And to meet the needs of young adults who are unable to participate in the workshop program, an occupational day center at Daughters of Israel Day Center on East 5th Street, was established.

Thus in 1957, in a brochure titled, "Information on Services and Activities," AHRC described six types of services and activities: clinics (The Morris J. Solomon Clinic for the Rehabilitation of Retarded Children at the Jewish Hospital in Brooklyn, the Theodora Clinic for Retarded Children at Flower and Fifth Avenue Hospital in Manhattan, and the Shield of David Institute for Retarded Children at the Shield of

David Home, Bronx); schools (at P.S. 84 Brooklyn, P.S. 72 Queens and the Joshua School in the Bronx-- for children ineligible for CRMD classes); training centers and sheltered workshops (a training center and sheltered workshop on East 27th Street, combining the earlier Brooklyn and Manhattan workshops); recreation services including: scouting programs for the young (cub and scout programs in Brooklyn, Queens and Manhattan), social groups for adolescents and adults (serving at this time about "122 young men and women [in nine groups] throughout the city)," general services (parent education programs, information and referral service, consultation service, coordination services) and what is in the brochure referred to as "The AHRC" (i.e., the opportunity for parents to meet other parents and to serve on committees in AHRC to help better their children=s lives).

One problem of AHRC and other parent groups at this time was that of competition and lack of cooperation. This was true in other states, but probably none so acutely as New York. The battling between the institutional-based groups and AHRC was recognized nationally. [end note 11] In Samuel Diggs' 1957 address to AHRC, he made the following remarks,

> "At the risk of being considered out of order on this night when you have so graciously paid me such a wonderful honor, I am going to fuss at you just a bit. What I am going to say, and I say this with sincere interest in the problem...I say with affection and great sympathy.
>
> "I am going to fuss at you because I feel so keenly the urgent need for united action-- we cannot afford the luxury of a divided house.
>
> "There is too much squabbling between various interests and between groups engaged in this fight to bring about better conditions for the mentally retarded and their families."

Diggs knew about the conflict between the institutional and community-based groups in New York through his involvement with NARC, which was notably concerned with the problem in the same way as Diggs appears to be in these remarks. He chose his words, carefully I imagine, given who must have been in the audience. Emotions ran very high about the issue of who 'really' represented the interests of mentally retarded persons in the State. When he was approached by NARC to reach a compromise with the institutional groups, Weingold was reported to say that "there was nothing to talk about." To the mutual benefit of all involved, these differences were eventually resolved by NYSARC at the state level, but not without a long battle. By 1957, the Sunshine League of Monroe, New York, one of the institutional-based groups, is listed as one of NYSARC's twenty-six chapters. But the Welfare League, the oldest parent group in the State, continued to fight AHRC about the issue of membership in NARC, among other things. It was also true that AHRC locked horns with the NARC on several substantive issues during this period and later, and that for a time AHRC dropped out of the national.[end note 12] During the 1950's much effort was unfortunately wasted by parent groups vying with one another for recognition and resources. To the detriment of their own interests sometimes they did not present a united front regarding their children's needs.

Despite this and other difficulties, AHRC was fortunate to close out the decade with three significant victories, all of which occurred in 1959. First was the passage on the federal level of social security legislation benefiting persons with retardation. AHRC and other parent groups around the nation had strongly pushed for this legislation in Washington. Then, in August of that year, the New York State Department of Mental Hygiene announced the formation of the Office of Mental Retardation that was to coordinate and develop all services for the mentally retarded in the State. It was placed under the directorship of Dr. Arthur W. Pense and charged with responsibility for both institutional care and the development of community programs. The creation of a state level agency to perform these functions had been urged by AHRC since its inception, ten years earlier. Finally, the American Association on Mental Deficiency, through its classification manual, officially changed its nomenclature from the language of "mental deficiency" to that of "mental retardation," and added a social component to its clinical assessment. This, as was described above, was a particularly proud moment for the founding parents.

At the close of the 1950's AHRC was a relatively small human services organization that had been remarkably successful in promoting the welfare of persons with mental retardation and their families through public education and legislation. It operated a few programs primarily for purposes of demonstrating their feasibility and to meet need where governmental support was absent or inadequate. By this time AHRC's focus had clearly become the "trainable" population, as a result both of the splitting off of the ACRMD, and because the need was far greater for those families with children for whom no legislative mandate or services existed. In 1957, for example, in a pamphlet titled, "Every Child Shall Have The Right," the Association says quite explicitly under the topic heading "With Whom We Are Concerned" that "We are concerned with the 'trainable.' " Some interviewees said that this focus also had to do with the developmental status of several of the founders children, and there may be some truth to this assertion.

Probably the most important thing it had achieved in its first ten years was to establish parent groups as the leaders of the field of mental retardation. AHRC created "professional lag." Dr. Samuel Kirk, in the **Annual Report, New York State Joint Legislative Committee on Mental Retardation**, is quoted as saying in March of 1960,

> "The public has gone so fast in their demands on what should be done with the mentally retarded in all areas-- medical, social, educational and otherwise-- that today we find not so much a cultural lag, but really a professional lag." (p.63)

The public, namely parents, had begun to lead the professionals in the field. Yet, for reasons largely unrelated to its own efforts and own successes in this decade, AHRC was about to make even greater strides forward in its maturation.

The 1960's: Becoming Kosher

Jack Gorelick, who was deeply involved in AHRC politics of this era, said that "the most critical event was Kennedy's election as President." This occurrence was to change the course of mental retardation in the United States.

It is not uncommon that the particular happenstance and human concerns of Presidents and Prime Ministers somehow appear on the social agendas of their societies. Most persons know that John F. Kennedy's family included a sister with mental retardation. The Joseph P. Kennedy, Jr. Foundation, the first private foundation in our country exclusively concerned with mental retardation, and the Special Olympics, today a worldwide sports association for people with mental retardation, are two conspicuous results of the efforts of the Kennedy family in this arena. But most people today do not appreciate the incredible effect that the Kennedy's going public with the story of their sister had on societal attitudes toward people with mental retardation. Gorelick states,

> "All of a sudden it was like...John F. Kennedy is my bosom companion, you know? And that is what happened. It was the aura of respectability that came bang like that! And that was a key event. That was a most important event

> psychologically for people in the field. We were kosher. Before we were traife, now we were suddenly kosher...After 1960 if you are a real American you are going to support mental retardation."

After his election to the Presidency, Kennedy not only spoke openly about his mentally retarded sister, but Eunice, one of the other Kennedy sisters, wrote eloquently in magazines about the family's situation. The effect was electrifying, not only in the United States but also abroad where, for example, De Gaulle announced that he had a daughter with retardation. Mental retardation had become a "shi-shi" social cause, and not something to hide away in the closet.

But the Kennedy's did not at all limit their efforts to private foundations and public education. President Kennedy created the President's Panel on Mental Retardation (PPMR) in 1961 (later becoming the President's Committee on Mental Retardation (PCMR)). His administration spearheaded legislation and policy that was to have a profound effect on the future development of the field. Some examples are, the recommendation of PPMR to reduce the census in residential institutions, the passage of the Mental Retardation Facilities and Community Mental Health Centers Construction Act in 1963 (beginning the flow of federal dollars into institutions), and the amendments to the Social Security Act in 1965 (establishing the Medicaid and Medicare programs). These were all accomplishments of, or as a result of, the initiatives of the Kennedy administration. The passage of the amendments to the Social Security Act in 1967 that created Intermediate Care Facilities for the Mentally Retarded (ICF/MRs), while not a direct result of the Kennedy administration, was a direct reflection of the different policy and legislation that his presidency brought to this area. With the Kennedys in the White House, the federal government had clearly 'entered the mental retardation business.'

Within New York State, the US Attorney General, Robert Kennedy, was involved in mental retardation during the 1960's largely as an advocate and as a critic of institutional conditions. He delivered many speeches in the mid-1960's, for example his October 17, 1964 address on the opening of the Institute on Mental Retardation at Queens College, in which he called for an overall attack on the problems of mental retardation, and a dedication of social resources to help these persons. He also was quite outspoken in his criticisms of the State when it came to the conditions of institutions, and was one of the first national political figures to speak so condemningly of them. In a **New York Times** article of September 10, 1965, he is quoted as saying conditions at Willowbrook were like "a snake pit." While it is not clear from his remarks that Kennedy wanted institutions closed in the state, it is the case that his remarks helped fuel the Deinstitutionalization movement that began in the early 1970's.

With more progressive attitudes and liberal policies, AHRC grew during the 1960's. In addition to the programs it already operated, in 1965 it expanded through opening an adult treatment center in Far Rockaway. A year later, a satellite workshop opened in Woodside, Queens. And a year after that AHRC opened a Saturday pre-school program in Queens, an Occupational Training Center in Brooklyn, and, with the Children's Aid Society, a preschool in Manhattan. At the end of the decade it operated a total of 16 programs, making it a moderately sized social service agency.

Entering the decade of the 1970's, AHRC had been in existence for just more than twenty years. It had already witnessed, and indeed helped bring about, a change in attitudes towards people with mental retardation and had participated in the development of new services for them and their families. The parent movement had become a major force in the field of mental retardation, and there was some evidence that what was just a hope of the parents two decades earlier, was becoming a reality. American society was moving towards kinder and more just treatment of its citizens with mental retardation.

CHAPTER 6 - DEINSTITUTIONALIZATION AND COMMUNITY INTEGRATION: THE 1970'S AND 1980'S.

> "Once the foundation was conceptualized and laid, and you had a strong organization, a lot of volunteers, a very active membership group, then it was really easy." -- Jack Gorelick about AHRC in the late 1960's.

The 1970's and 1980's were tremendous periods of growth for AHRC. The decade began with the opening of Fineson House in 1970, AHRC's first residential service. It was funded by the Office of Mental Retardation as one of several experimental community "hostels" for adults with mental retardation as an alternative to institutionalization. The development of community residential alternatives was one of the last elements of the long-range plan to be put into place. And while AHRC was clearly committed to such places for the children of member parents before the Willowbrook exposé, as will be seen, it was in fact the massive ideological, institutional and legislative changes that took place in the 1970's that were responsible for the incredible growth of the agency during this period. The basis of a strong organization was already in place before these events occurred, but the historical conditions of this period provided an ideal growth medium for AHRC.

On a national level, for many reasons not the least of which was the parents' group movement, we began to see legal and legislative changes that furthered the interests of children and adults with retardation in a way never before seen in our society. The beginning of the decade saw the Pennsylvania Association for Retarded Children vs. Commonwealth of Pennsylvania, which in 1971 established the right to education for children with disabilities, and the right to due process in educational decisions. The next year Wyatt vs. Stickney in Alabama established the constitutional right to treatment and in the least restrictive environment. In 1972

Amendments to the Social Security Act created Supplemental Security Income to provide financial subsidy to persons in need, including those with "developmental disabilities." [end note 13] In 1975 three major pieces of legislation were passed, indicating how mobilized around issues of disability the society had become. In that year President Nixon signed an executive order reaffirming the nation's commitment to returning one-third of the two hundred thousand persons with mental retardation living in institutions to the community. Congress passed Public Law 94-142, the Education for all Handicapped Children Act, mandating free, appropriate public education in the least restrictive alternative for children with developmental disabilities. Congress also passed the Developmental Disabilities Assistance and Bill of Rights Act, which established the legal definition of the term, created Protection and Advocacy systems, developmental disability planning councils, and university affiliated facilities in each state. Then, in 1977, in Pennsylvania Association for Retarded Children vs. Pennhurst State School and Hospital, the courts established the guarantee of equal protection under the 14th amendment to the Constitution as applying to people living in mental retardation facilities. These legal and legislative developments for persons with physical disabilities (such as Section 504 of the Rehabilitation Act of 1973) created the legal substructure under which problems related to the overall welfare of persons with disabilities in America could be finally addressed.

The effect on the educational system was to place the burden of education of children with disabilities squarely upon the shoulder of the State, and this, of course was what AHRC had wanted from its outset. This meant that AHRC no longer had to be in the business of running classes, that the Board of Education now would have to provide for the educational needs of all school-age children with mental retardation. Although it took twenty-five years since the formation of AHRC for this to become official educational policy, these legislative changes must be seen as at least partially a result of AHRC's perseverance and patience. AHRC continues to this day to operate classes for children not provided with education by the Board of Education. It also employs an educational advocate since the mid-1970's to ensure that those attending Board of Education programs receive the education to which they are entitled.

At the same time the publication of **The Principles of Normalization** by Wolf Wolfensberger in 1972 had created an ideology within which both parents and professionals came to evaluate their programs and efforts. Normalization was a Scandinavian paradigm that entailed a commitment to creating normal conditions of life for people with mental retardation. Its popularity had been mounting during the 1960's through the public speeches of well-known advocates such as Bengt Nirje in Sweden and Neils Eric Bank-Mikkelsen in Denmark (the originator of the approach). It was described, popularized and operationalized in the United States and Canada by Wolfensberger, and by the end of the 1970's was **The** philosophy of our field. It was known to administrators, professionals, direct care staff, and even to some of the residents at the State Hospital where I worked in the 1970's. Normalization articulated a new value base for services, one that enhanced the community inclusion of persons with disabling conditions.

Deinstitutionalization in the 1970's

As mentioned in the title of this chapter, the other major movement in the beginning of the 1970's was Deinstitutionalization. Beginning in Scandinavia in the 1950's, this movement was already underway in the 1960's in the United States. We have already heard about Robert Kennedy's efforts to expose institutional conditions in the mid 1960's. In addition, parents associated with the various institution-based groups demonstrated for betterment and/or closure of state schools (although before the television exposé of Rivera they described themselves as "yelling into the air"). Further, there had been many newspaper exposés replete with photos. For example, on Staten Island, Jane Curtin, a reporter for the **Staten Island Advance**, wrote several articles exposing the conditions at Willowbrook in the early 1970's. [end note 14]

But it was the television exposure of conditions at Willowbrook State School by then ABC television reporter Geraldo Rivera that served as the historical catalyst for the closing of institutions in New York and around the nation. The horrifying images of large numbers of children naked, restrained, lying in their own feces, congregated together without supervision, were to create a public and political uproar that previous coverage failed to do. On the 25th anniversary television special by Rivera of the Willowbrook exposé, when a parent who had picketed Willowbrook before Rivera arrived said to him that he was responsible for finally gaining the public's attention, Rivera responded by saying, "It was the pictures." This was probably a correct reflection.

Once Rivera televised the series of special programs exposing the conditions at Willowbrook, it was not long thereafter that a coalition of organizations filed suit against the State for violation of the civil rights of their children. NYS ARC was one of the groups that sued the then Governor, Hugh Carey. In fairness to Carey who had just been elected, a less sympathetic former-Governor Malcom Wilson had allowed conditions at Willowbrook to seriously degenerate under his administration. As will be remembered from above, Willowbrook State School was taken back from the Department of the Army in 1948 and officially opened in 1952. It had been originally designed to house about 2,000 people with mental retardation. By the end of the 1960's, Willowbrook housed over 6,000 persons and had become the largest institution in the world for people with mental retardation. This expansion was largely due to the use of the facility as a dumping ground for the New York City Department of Social Services. All kinds of people ended up at Willowbrook. There were normal persons with delinquent backgrounds, abandoned children without any disability, children and adults with disabilities but not mental retardation, children and adults with multiple disabilities and profound mental retardation, and all other levels and types of disabilities. There was a building devoted entirely to babies, which by the time of the exposé housed hundreds of infants. One worker of that era recalls visiting the baby building which was "completely silent," the infants having learned quickly the futility of crying.

The overcrowded conditions at Willowbrook were exacerbated in the1960's by budgetary cuts. These cuts created dangerous and critically substandard conditions at the facility. Many buildings would have four or five staff to care for up to a hundred residents. The average feeding time for children who could not feed themselves was about three minutes. This was done by shoveling mashed up food into the children's mouths, leading to the most common form of death for children at Willowbrook, aspiration pneumonia. Bernard Carabello, an eighteen year resident of the facility who had cerebral palsy but not mental retardation, recalled having to drink out of the toilet bowls during the summers, because the kitchens were closed to the residents. He recalls having the "hell beaten out of me" when he transgressed the rules or when a staff member did not like him. There were many cases of death at Willowbrook reported in the newspaper, often deaths caused by other inmates. Less known at the time were the facts of resident life such as forced sexuality, institutional homosexuality, and institutional peonage. Though technically legal, residents of Willowbrook were medically experimented upon, often with permission that by today's ethical standards would not be considered in any way adequate. Willowbrook for many was a concentration camp-like existence whose revelation to the society by Rivera could have called for nothing less than its closure.

This is precisely what occurred. Governor Carey decided that it was not necessary for those suing the State to actually go through the process in court. He was willing to close Willowbrook without suit and filed a no lo contender movement in court. This led to what was called "The Consent Decree" in which the State of New York agreed to close Willowbrook under the supervision of a court appointed Board of Monitors. The Consent Decree established a legal precedence for closure that was employed in similar suits around the country. It also helped establish a process by which Deinstitutionalization could be achieved. This included the development of community services and residential options for individuals that had been formerly housed at Willowbrook. Finally, the exposé and Consent Decree established an unfriendly political climate for institutions, which have been under attack since. The option of institutionalization was no longer considered good medical advice and this also added to the need for the development of community services.

Of course these developments created ideal conditions for the creation of community programs and residences by agencies in the New York area. It was this era that saw the expansion of many community agencies around the City. The State was committed to closing at least Willowbrook, and possibly other institutions. There was a national policy of depopulation and the legal basis for establishing community services for the population. The State had no choice but to follow along with appropriations and the stage was set for massive expansion of agencies. Judy DeIasi, the current Associate Executive Director of AHRC remembers that period during her 1998 interview.

> "...it was easy to grow. Michael was a good Executive Director but anybody could grow, anybody. You know the money was there. You want to open a one hundred and fifty person day treatment center?...Open it...So the agencies grew...People...knew an opportunity."

While this characterization of the situation was true for many agencies that seized opportunity and embarked in virtually unplanned growth, AHRC maintained a different position following Willowbrook. First it led the way in the formation of an Interagency Council (IAC) reconstituted more along the lines of a trade association.

The IAC became an effective planning and action network and through it agencies were able to control the growth of community services for adults with mental retardation. For example, through the IAC Goldfarb advanced the position that all new programs should include equal mixes of 'class clients' and adults from the community who are on the waiting list, a recommendation that was to have positive repercussions in the lives of adults with mental retardation in New York City.

Secondly, AHRC did not immediately get involved with Willowbrook 'class clients,' as some other agencies did. It was a conscious decision not to develop programs until community services were at least planned and to some degree developed, and until AHRC created management structures to accommodate such growth. Thus while AHRC was considered the lead agency in the area, it was not quick to develop services for the Willowbrook clients, to some degree angering the State agency by its seeming unwillingness to proceed. But Goldfarb remarks, "...in the end it was good for us." Goldfarb promoted the agency to grow only after the necessary political and management groundwork had been put into place.

But as DeIasi's remarks indicate, these were the "Golden Years" of the mental retardation movement. It is thus remarkable, but not entirely surprising, that the agency experienced a more than ten fold growth in staff size from two hundred employees in 1975 when Goldfarb became Executive Director, to two thousand five hundred employees in 1998. When Goldfarb came to AHRC its budget was approximately two million dollars. Today, it is over ninety-five million. When the residents at the 30th Street supported-apartment complex were asked about the changes in AHRC over the years, the first thing that came to their minds and that they strongly expressed was, "Now they are very big...They grew over the years!" (Gilda Lindenblatt)

In 1971 AHRC began to operate its own camp, Camp Catskill. In 1972 it opened another Occupation Day Center in Willamsburg to provide programs for children attending the Brooklyn State School. In 1973 the Association opened the Bronx Adult Day Center on Mayflower Avenue. In 1974, as a sign of the progressive educational policies described above, AHRC transferred 13 classes it had operated for children with severe and multiple disabilities to the Board of Education (actually leading to a reduction in program size but in an ethically desirable way). In 1976 the Melvin Krauss Residence opened on East 5th Street in Manhattan. That same year, Jack Gorelick opened a diagnostic and treatment clinic at the main office in Manhattan. The clinic, the first of its type to be headed by a non-medical director, provided diagnostic, medical, psychological and counseling services, as well as being the entry point for referral, group work, recreation and camping. In 1977 with the efforts of AHRC's Blue Feather Auxiliary, AHRC opened the Blue Feather Early Childhood Program at P.S. 312 in Brooklyn, aimed at providing early intervention and education to children ages two to five. In 1978, the agency opened the Linden Boulevard Adult Day Center in Brooklyn, and the Plato Malozemoff House in a brownstone off Washington Square in Manhattan. Finishing in a flurry of program development at the end of the decade, AHRC opened five community residences and the House in the Country program in 1979. The new residences included: Greenberg House in the Bronx, Linden Boulevard Residence in Brooklyn, Petersen House and Building #53 on Staten Island, and Striar House in College Point, Queens. This same level of expansion was to characterize the 1980's, as we shall shortly see.

Before doing so it is interesting to note that AHRC had been involved with the production of the feature length documentary "Best Boy" at the end of the 1970's. This film concerns the residential placement of a man, Philly, who had lived with his mother well into his 50's. It poignantly portrayed the dependency of the mother on her son, and the ambivalence both felt at separation, but also the feeling of freedom experienced once the separation was achieved. The film was made by Ira Wohl, the cousin of "Best Boy" and was awarded the Academy Award for full-length documentary in 1980. The agency thus continued its early commitment to public education through media. [end note 15]

AHRC was one of the New York agencies to lead the way in the late 1970's in the establishment of self-advocacy groups within its programs. Self-advocacy is a self-help, civil rights style movement in which persons with mental retardation speak out on their own behalf. The movement began in Sweden in the 1960's when parents asked their children what they wanted to see in the supports and services given to them. It took form in the United States through the "People First" movement that began in Oregon in the beginning of the 1970's. People who had been living at Fairview Hospital decided that they were going to organize a group that would represent their interests at conferences and in government. Someone in that group used the term 'people first' and it caught on. People First chapters began opening all over the country in the 1970's. AHRC and other New York providers, while wary at first, ultimately did support the organization of these groups within their programs and residences. Self-advocacy was a risky experiment at first, but today is regarded as a necessary option for people with mental retardation who want to organize around their own interests.

Yet another development of the late seventies was the arrival of I. William Stone to the agency as a member of the Board. Stone is the father of Howie, his son who was born with multiple disabilities including cerebral palsy and mental retardation. Howie, as he put it in his interview, "always fell through the cracks." When he would inquire about agencies serving persons with physical disabilities he was told to go to one serving mental disabilities. When he would inquire at those agencies he was told to go to agencies serving people with physical disabilities. Stone's long-term involvement with the agency was to ultimately sensitize it to the needs of persons with mental retardation and physical disability, and particularly to the importance of addressing issues of accessibility in residential and adult services. He commented in his interview,

> "I am willing to take some credit for making AHRC aware of the needs of the multiply handicapped, particularly those who are physically handicapped. There is no question that I fought for that. Agovino [the first fully accessible residence operated by AHRC-DG] would never have come about if I had not kept fighting. It took seven years and it could have easily been too much trouble and set aside. Yes, what I tried to do was make the other members of the Board aware of the fact that if we opened a new residence it had to be wheelchair accessible. Definitely, I pushed this since the day I came on. When I first came on there was no focus at all on the physically disabled mentally retarded." [end note 16]

The presence of Stone on the Board and his emphasis on serving persons with physical as well as mental disabilities was important to AHRC. He helped to put the agency a position of being a couple of decades ahead of its competitors in terms of issues of accessibility.

The changing status of AHRC during the 1970's can be summarized through the following metaphor. When AHRC began it was the big fish in a very, very small pond. By the end of the 1970's it had become a big fish in a big pond. Many other agencies "knew an opportunity" and had taken advantage to greatly enlarge their mental retardation programs. Some of these, such as the Young Adult Institute (YAI), an agency formerly headed by David Bond but taken over by Joel and Phillip Levy during the 1970's, was particularly aggressive in public relations and agency name promotion. In fact, all agencies became more sensitive to these matters as their budgets and expertise permitted. But certainly by the end of the decade AHRC was no longer the only premiere agency in the city. While it was, and probably always will be regarded as the "dowager queen" (Goldfarb interview) of agencies for people with mental retardation, it had taken its place among other significant large service organizations. Its role as the leading agency in the field, however, remained fairly constant, and is still recognized today.

The 1980's: The Era of Community Integration

The progressive changes in policy and legislation continued throughout the 1980's. This decade had been named "Decade of the Disabled" by the United Nations. Internationally the UN sponsored events and conferences during the decade that culminated in the passage of the United Nations **Standard Rules for Equalization of Opportunities for Persons With Disabilities** (Resolution 48/96 of the General Assembly of the United Nations, passed December 20, 1993). In Europe, high levels of professional activities and meetings under the HELIOS I and HELIOS II programs moved both policy and program models forward during this period. The European Commission passed its own version of the **Standard Rules** in 1996.

Paralleling the increased global awareness of disability issues, in the United States, several changes in legislation came early in the 1980's that profoundly effected the services for people with mental retardation. First was the amendment to the Social Security Act in 1981 that came to be known as 'the Katie Beckett Waiver.' This allowed children to receive care at home who otherwise would have previously needed institutionalization for eligibility for Medicaid. Then, the so-called "Medicaid waiver program," part of the Federal Omnibus Reconciliation Act (OBRA) of 1981, created the possibility of diversion of Medicaid funds into small community settings.

Of course the most significant piece of legislation to come out of the 1980's for persons with disabilities in the United States was the Americans with Disabilities Act (ADA). While signed into law in 1990, the disability rights movement, including parent and other groups, participated in a decade long political process that resulted in the ADA. Similar in emphasis to the **Standard Rules**, ADA aims at ending overt discrimination and isolation of people with disabilities within the society. Its provisions, considered by many 'radical' when the bill was first passed, include regulations regarding accessibility in public transportation, public buildings, public media and communications, equal opportunity and reasonable accommodation in employment, and other provisions that, when fully implemented, would substantially enhance the quality of life for people with disabilities.

All these developments during the 1980's were expressions of the liberal sentiment that were part of the Golden Era of mental retardation, when funds were available to those who saw an opportunity. While a conservative backlash against the expansion of social programs for needy persons was beginning to gain power, the decade was still one in which program growth was fiscally feasible for mental retardation agencies. Deinstitutionalization proceeded slowly. Persons coming out of institutions and those in the community who were adult and needed residential placement, were the human need upon which programs were built. Funds were still generally available to agencies opening up community-based programs.

In 1983, AHRC opened a residence for eight men and women with profound mental retardation and multiple disabilities, the Ozone Park Residence in Queens. In 1984 the Phyllis and Harold B. Jacobs House was opened in an Upper West Side brownstone. In 1985, a community residence was started in the Bronx, the Elena Agovino Residence. That same year the Blue Feather Minna D. Bober residence was opened in Brooklyn. Two additional summer programs were also added in 1985, one in the Pennsylvania Mountains (House in the Poconos) and one at the Jersey shore (House on the Seashore). The Harriman Lodge, a summer resort program for adults with mild mental retardation, opened in 1986 in the Catskills. HIRE (Helping Industry Hire Reliable Employees), a supported work project that involves job training and placement in competitive employment was initiated in 1986. In 1987 AHRC began operation of the Paula & Anthony Fisher Adult Day Center on 10th Avenue in Manhattan. In 1988 the Agency expanded further by opening the Gruenstein Residence in Holliswood, Queens, and two supervised apartment programs in Brooklyn, thus moving into the currently popular program model relatively early. In the Bronx in 1988, AHRC began its Bronx Seniors in Action program, aimed at meeting the needs of elderly people with mental retardation. These new programs significantly expanded AHRC's array of services. By the end of the 1980's it was a large agency, by any standard, with an annual budget of about thirty million dollars.

In 1985, AHRC began providing services and supports focusing around the issues of adult siblings of brothers and sisters with mental retardation and other developmental disabilities. The Sibling Program was one of the earliest attempts by a human service agency to deal with this group's needs. Jack Gorelick remembers,

> "I started the sibling group...and you would also want to talk to Meyer Schreiber about this. He worked with many of the kids. We were one of the first in the country to work with these kids. And the parents would say, "What did they say?"...You know, the most difficult job I ever had was working with siblings. The anger..."

What the pioneering work of Schreiber and Gorelick revealed was that the complex emotional issues found in all families are even more complex, even more intense, when the family has a child with mental retardation. AHRC became a leader in establishing sibling support groups and supports. Dr. Edmund Haddad joined AHRC in this effort, and with Dr. Thomas Powell, the then Director of the University Affiliated Program in Connecticut and himself a sibling, established a national sibling network that still thrives today.

Before looking at AHRC in the 1990's and the changes the agency underwent in its tremendous expansion, a last contribution of AHRC leadership in the 1980's, particularly Goldfarb and Gorelick, should be described. They were considering ways to enhance staff quality in AHRC programs. AHRC, as other agencies in the City, faced a crisis in staffing at the direct-care level. The low pay of these jobs, relative to other forms of employment, created a virtual crisis in direct care staff quality in many agencies. Anyone with a high school diploma or GED could basically work for an agency serving persons with retardation. They needed no training. Staff turnover in New York City was alarmingly high, with some agencies reporting almost complete turnover within a year at the lowest staff positions. AHRC attempted to keep pace with the salaries of the State in part to address this problem. Even so, staff quality, not only at the direct care level but at all levels, became a preoccupying problem for AHRC in the 1980's. The solution Gorelick and Goldfarb came up with was to have the higher education system in New York, particularly the Community and Senior Colleges of the City University of New York, train the needed workers and professionals. The idea of establishing a Fellowship program for workers was also part of their solution.

Goldfarb recalls,

> "And so we designed this twenty years ago, the idea for fellowships was mine, the notion of using the university was his. And we put this together and marketed the thing for years and couldn't get anybody to bite... We met with everyone and we still couldn't get it moving..."

He then recalls sitting in a meeting with John Kennedy, Jr. in 1987.

> "I said, 'Wait a minute. I've got this idea you might be interested in. We're

> working with CUNY on this institute to train workers in the field. What it really needs are Kennedy Fellows...He liked that and I went back to Jim Murphy and the Chancellor Joe Murphy...and I told them, we got Kennedy interested. The thing took off."

The Foundation had given substantial seed monies to the cousins of the Kennedy family to use in matters related to disability. John Kennedy, Jr. had taken a particular interest in the quality of the direct care work force issue, and had become involved with the City University initiative. He took a direct interest in the formation of the initiative, attending planning meetings at the City University with Jeff Sacks, his adviser and friend who had initially introduced him to Gorelick and Goldfarb. The initiative took off partially because the Kennedy name had been leant to it, and partially because Kennedy invested in the Kennedy Fellows program, and also in supporting the salary of a staff person in the central CUNY office, Dr. Bill Ebenstein, to coordinate matters related to disability education, training and research.

The eventual success of the Goldfarb-Gorelick solution to workforce education and quality issues was, as in the past, a particularly innovative contribution from AHRC to the field. The CUNY Consortium for Disability Studies, and the Kennedy Fellows Program, are two of the first examples of programs of this type in the country. Today it is a huge success involving hundreds of Kennedy Fellows all over the City. Goldfarb recalls a recent meeting of the Kennedy Fellows that he attended.

> "The first speaker was Jim Murphy. He talked about the fact that Jack Gorelick and I created the idea. He says, 'Sit in front of the room'...which I don't usually do. And then Kennedy gets up and talks about the visit to my office during which the idea was presented to him. And then Jeff Sacks gets up...he remembered. They all remembered little pieces. I was so touched just that they remembered."

It is well that people should remember the contribution made by these men. Their perseverance over twenty years in promoting this idea and their eventual success in some ways reminds one of the efforts of the founding parents. Mike Goldfarb and Jack Gorelick should be proud of the role they played in creating this innovative training model. AHRC played a ground-breaking role in the modern worker training movement. [end note 17]

In the decade of the 1980's, despite the fact that AHRC was no longer the only big fish in the pond, it continued its tradition of leadership in the field of mental retardation by establishing innovative programs such as the CUNY Consortium and the Sibling Network.

CHAPTER 7 - AHRC IN THE 1990's AND INTO THE 21ST CENTURY

> "Minna* once came into my office and said to me, 'You owe us a lot.' I said, 'Minna, what do I owe you?' And she said, 'We made you a better person.' " -- Michael Goldfarb, recent interview. (* = Minna D. Bober, Esq., founding parent of AHRC)

> "I never forget why I am here. Michael never forgets why he is here... You cannot permit something to look shabby, because there is a parent watching." -- Judy DeIasi

> "The privilege of being involved with AHRC is that it is suffused with love."- Jim Murphy, AHRC President, 1974-77.

Organization and Services

A visitor to AHRC's main office on Union Square would find the following basic facts from its "General Information" brochure. Today AHRC is one of the largest consumer-based not-for-profits in the City with a membership of over twelve thousand. AHRC serves over seven thousand people with disabilities of all ages and levels of disabilities, and provides education and training, counseling, case management, referral and advocacy services to families. The agency employs over two thousand five hundred staff, at more than eighty-five service sites, with an operating budget of over ninety million dollars. It has tripled its operating budget since 1990.

Now in its fiftieth year, AHRC is organized into several Departments that are responsible for operating thematically grouped programs and services. The Department of Family and Clinical Services functions as a gateway to all further service provisions in the agency, provides a wide array of clinics and also acts as a referral service to other social service agencies. Clinical services include group and individual counseling, developmental evaluation and testing services, medical services, habilitation services, service coordination (case management), legal and guardianship services, future care planning, the sibling network, and an alcohol and substance abuse clinic (this being the first of its type and licensed by the New York State Office of Alcohol and Substance Abuse Services). Also within the Department of Family and Clinical Services are two other innovative programs, the Francesca Nicosia Fund (Family Reimbursement Project) begun in 1991 and the In-Home Behavior Management Program. The Francesca Nicosia Fund allows parents to determine what resources they need to improve the quality of their life. The In-Home Behavior Management Program provides training to families trying to cope with destructive, aggressive and otherwise difficult behaviors of children in the home. The Department of Family and Clinical Services also runs the Bronx Early Childhood Direction Center, an information and referral service to parents of young children with disabilities.

The Department of Residential Services provides a variety of residential options to almost four hundred people with developmental disabilities in the five boroughs. These residential options include Intermediate Care Facilities, community residences, supported apartments and independent living arrangements (individual residential alternatives or IRAs). Additionally, in-home residential habilitation services are provided to families to help meet care giving responsibilities. Respite services are also provided to families who, for a variety of reasons, need "time off" from their caretaking responsibilities.

The Department of Camping and Recreational Services operates programs for over eight hundred people with mental retardation annually from ages five to eighty. These include camping, vacation and recreation services that are provided to over eight hundred people. The Department operates Camp Catskill, and Harriman Lodge, and a referral service to other camps. The Family Weekends in the Country Program, where families can spend a "get-a-way" weekend in the Catskills is also available. The Recreational Services Program offers a large variety of recreational programs in the five boroughs, including theater, photography, arts and crafts, sports and local travel.

AHRC operates Early Intervention, Early Childhood and Related Educational Services known also as the Blue Feather Early Learning Programs. AHRC began early intervention programs in 1976, with the opening of the Blue Feather Early Learning Center in Brooklyn. This was years prior to the passage of PL 99-457, the Federal Legislation of the late 1980's, today known as "The Individuals With Disabilities Education Act (IDEA)," that makes early intervention and education an entitlement to children with handicapping conditions. These Federal provisions currently have to be implemented and monitored by each State (and the way this evolved in New York State could itself be a book). Early intervention services in New York City are monitored by the New York State Department of Health (ages birth through three), the State Department of Education (ages three to five), and, for programs for children three to five years old that are located in the City, by the City Board of Education. The Blue Feather Early Learning Centers provide a variety of services to children ages birth to five years old. These include six Center-Based Special Education Preschools (the Astoria Blue Feather Center, the Howard Haber Early Learning Center (Bronx), the Bronx Blue Feather Early Intervention Program, the Brooklyn Blue Feather Early Learning Center, the Jennie Knauff Children's Center (Bronx, serving children who are medically fragile) and the Esther Ashkenas Center (Manhattan). The Department also provides specialized Applied Behavior Analysis Programs for children ages three through twelve diagnosed with autism. Beyond this, the Department provides itinerant special education and related services to children ages three to five in mainstreamed programs, early intervention discrete services for children birth to three who do not require comprehensive programs or placement, and advocacy services to assist families in getting appropriate services for their children.

AHRC operates Adult Day Services ranging from programs that are geared to individuals who require high levels of supervision and training, to assisting individuals in competitive employment. AHRC currently serves more than seventeen hundred individuals throughout New York City in three day habilitation programs (a goals-oriented program involving recreation, education, culture, community exploration, voluntarism and work), three vocational workshops (wherein structured work environments are offered for those who need them), three day treatment centers (in which abilities of the individual to function more independently and in the community are fostered), as well as specialty programs and numerous competitive and supported employment settings. AHRC also operates an array of services specially tailored to the needs of people with Traumatic Brain Injury (TBI), TBI Community Support Services. The Seniors in Action program, in which individuals fifty and over participate in various activities, including senior programs with their non-disabled peers, is also administered by Adult Day Services. AHRC programs are funded by a complex mixture of federal, state, third party, private donations, and grants.

AHRC has become over time, in sociological terms, more of a gesellschaft, which evolved from the founders' vision and their earlier smaller, family-like organization (gemeinschaft). For AHRC to be what it is today required a change in self-image as well as modus operandi. This evolution was a central topic in the interviews with current administrators, Judy DeIasi, Michael Goldfarb, Bob Gundersen and Gerry Maurer.

Michael Goldfarb came to AHRC in 1975 after "answering a blind ad." Goldfarb had come from a family in various ways involved in human services and medicine. His father was a psychiatrist of some repute who had actually done some studies of the impact of institutionalization on children. Goldfarb had rejected a career in philosophy, although he acknowledges its contribution to some of the skills required of his job. He had apprenticed at a mental health and child-care agency as an administrative assistant, and then served as a Director of a small mental health service, Brooklyn Psychiatric Centers. Jack Gorelick who was acting Executive Director at the time made it clear that he did not want the position, but preferred to run the AHRC Clinic. Goldfarb was hired as AHRC Executive Director in 1975 after an extensive search process. He has remained Executive Director for the past twenty-three years, substantially affecting the planning and growth of the organization, and helping to maintain AHRC's position as the leading agency in its field.

This being said, it is important to recall the epigram to this chapter in which Minna Bober formulates for Goldfarb the effect AHRC had upon him as a person. Goldfarb's task was different from that of the founding parents. When he arrived, AHRC presented a strong organizational culture that defined him and the other administrators who have come to the agency.

> "They changed the kind of person I am. And that is a really critical issue. Good Executive Directors of ARCs...have to be able to internalize the culture of the ARC. Basically, they changed me a lot...One of the first weeks I was here, Walter Redfield's wife, who was then alive, and Betty Pendler, walked into my office and sat me down and told me what it was all about. They told me that this is a **parent** organization, driven by **parent** values, and that if I wanted to stay here I was going to have to learn that. And they sat me down and that is what they did...So, some of my contribution to this organization came from becoming the person they wanted me to be...The culture defines

> the people who work here as much as the people who work here define the culture."

Thus, it is important to understand the dynamics of management in AHRC, especially the relationship to the Board and the organizational culture. Only then can one appreciate the how things worked when Goldfarb became Executive Director.

He recalls another early AHRC 'right of passage,'

> "...the first two years is the period when you are tested and tried...and the first two years were challenging. There were things that the Board wanted fixed and changed. And there were things the Board did not want to see touched. There was also a situation where the Board wanted to see things changed but didn't understand the price that would have to be paid to experience those changes...Members of the Board, many of whose children and brothers and sisters were in the programs, had to feel comfortable with me as somebody who was comfortable with their children, brothers and sisters. And, in fact, one of the Board members said, 'If my son comes over and hugs you, are you going to be comfortable?' So that personal level of comfort with people with disabilities was a real test.@

The presenting culture of the organization was and is most clearly expressed by the AHRC Board. Many other parent organizations founded in this era were until recently run by parent-dominated Boards. AHRC still is. When Goldfarb took over there was a very active Board.

> "Yeah, run by parents and other family members...Very much similar to the Board we have now but with some differences...Very strong committee structures. The committees were very much involved in policy-making for the

> organization. Very much a functional and active Board."

One of the strengths of the AHRC Board, sometimes lacking in other similar organizations, was its appreciation of the difference between governance and management. In the early days of AHRC, such a distinction was virtually impossible to make. As AHRC grew larger and the Board older, it became more comfortable with allowing agency management to run programs (the operating budget at this time was over $3,400,000 with over 200 full time employees. Direct management of operations by the Board would have already been impractical). Goldfarb recalls,

> "It's very clear to me that the Board knew, when I got here in '75, the difference between a member of the Board and a Chief Executive Officer, and we were very comfortable with that division of responsibility. That was very useful and very helpful."

But he also learned something else immediately about the Board and its policies.

> "Protection... is the primary driving force in the organization. That sets us apart from other agencies because, although most of them were founded by consumers, very few of them have retained consumer Boards. Consequently, protection, though it is an important element of design in other agencies, doesn't occupy the primary position that it does here."

In many of the interviews I conducted we discussed the issue of AHRC's current reputation as a somewhat conservative organization, a reputation that has changed over the past few years. Generally speaking the "protectionist" orientation characteristic of AHRC services and programs has been critiqued from the various ideological positions that have evolved since Goldfarb joined the agency. Generally speaking, the protectionist philosophy characteristic of AHRC's programs came into conflict with various concepts formulated by academics. Goldfarb comments,

> "I think you need a safety net. I think you need to recognize that the people we serve really have limitations, whether you want to call them that or not, whether it is politically correct or not to say. They really have limitations that disadvantage them in their environments, which are neither designed nor prepared to accept them. And one of the things that infuriates me about some academics in the field is their belief that we should destroy site-based programs and move on to "natural support." I mean that is basically a reactionary fantasy. You don't have to pay for anything...you just throw people out on their own...a Darwinian view I guess [clearly being sardonic now] I guess we hope they survive...".[end note 18]

Nobody on AHRC's administrative staff felt at all embarrassed about the fact that AHRC took this position with respect to its policies. Indeed they were quite convinced of their position and proud of it. This can be seen in Judy DeIasi's remarks. Judy was initially a Special Education Teacher who ended up working for the Office of Mental Retardation and Developmental Disabilities, eventually as Chief of Community Services in Queens. She had been a caseworker who placed clients from Willowbrook to community settings, and who had learned a lot about administration from her boss, Barbara Bloom. "Michael hired me," Judy says, "because I gave him a hard time." Closer to actual reality, as we shall see shortly, DeIasi fit into AHRC's plan to build the management team needed to accommodate future growth. Goldfarb had brought Bob Gundersen into the agency in 1984 to help structure management to meet the needs of the multimillion-dollar agency AHRC had become. Gundersen came from a management, not program, background, while DeIasi was brought on to administer programs.

During our interview, she devoted considerable time to remarks about AHRC's current viewpoint about inclusion.

> "I'm worried about so many of our people who have limited judgment. There are many issues coming out of the community...so much good has happened. And then there are issues that are really problematic. A new issue for me...this month...is credit cards. We've got two people with over $40,000 in credit card bills... And I was talking with somebody in Albany who hasn't run anything in twenty years...he does program planning...and he said, 'Isn't that great Judy?' You know like isn't it great that the problem they have is like everyone else's? And I don't have that reaction...They don't understand how they are going to pay $40,000 in credit card debt with a $7,000 salary. There are real issues."

DeIasi continues,

> "There are real prices to be paid... I think bringing people up with the expectations of full inclusion sometimes hits you in the face once they are out of school. When I look at a group home of ours...like 81st Street...they've been together. They're a family. There is love and trust there. In contrast, I know someone whose mom was one of those fighters for inclusion. She made sure he got into an integrated high school. And he has got nothing to do now. He doesn't see himself in any special program, and he doesn't understand why the blond sitting next to him in the college course he is taking...won't go out with him. So he goes out every Saturday night with his parents to the movies...he doesn't belong anywhere other than tagging along with his mom and dad...and I guess he'll tag along in the future with his sister. He'll be the uncle who lives with his sister...you know? But there is a real price compared to the folks at 81st street."

DeIasi and Goldfarb echo the sentiments of the AHRC Board. The preference is protecting persons with mental retardation. This is AHRC's way. While the organization reflects some of the changes in the field such as the "right to choose," at the heart of the AHRC philosophy is the parental urge to protect an offspring who cannot adequately do so him or herself. The administration has to internalize the values behind this urge, and utilize them in the day to day running of the agency. [end note 19]

Goldfarb related an anecdote about Jerry Weingold that went like this.

> "They felt guardianship [as had been written into law by Weingold and others] was intruding into the lives of people with disabilities, preventing them from living independently. There was a lot of chatter about 'dignity of risk.' And Jerry Weingold's response was, 'Does that mean you want to give people with mental retardation the right not only to climb to the top of the ladder but to fall off as well?' And to some extent that is how we view it."

The Board has supported the growth of AHRC over the past twenty-five years. Expansion was not undertaken for the same reasons as private business, in which survival may depend on the size of one's operation. Nor was it to be the biggest fish in the pond. Goldfarb comments regarding the growth in size of the agency,

> "...my feeling was always that unless we got a lot bigger, we could really not do what we intended to do anyway...and that we couldn't protect [certain programs]. We have a lot of services that nobody wants to pay for. These services can survive in an agency that's large, but could not survive in a smaller agency...Services like guardianship and advocacy that nobody would pay for. The only way we are able to do this is to be large enough and efficient enough to be able to either generate revenues within the program

> that are generally applicable to some of these new services..., or to run the operation efficiently enough to loosen up some funds that might otherwise have been spent on some program...We operate an agency in the black so that we serve people better and operate programs that would otherwise be in the red."

These are the real motives in the expansion of AHRC, providing an array of services that are thought to be necessary for the quality of life of residents and program participants. DeIasi said,

> "That's the way this agency functions. There is never a question if a person with a disability needs something...if a person needs something, we'll do it. You never think twice about a client issue, ever."

The expansion and diversification of services that makes it possible to provide the needed array of services, requires both a reconceptualization of the organization in terms of its self-image and management capacities. Thus in the late 1970's management purposefully set out to change the way AHRC operated, including its self-image. Goldfarb describes what he was attempting to do,

> "We made a decision... about fifteen years ago. I went to a presentation by Lou Brown, whom I had never heard at that point. And by the time he finished I knew that it was time for us to begin to look in some new directions. And so I brought him here and he talked to our staff and our Board. I brought my staff and Board together and we changed a lot of attitudes. But what we try to do is to incorporate some of the newer approaches into what we do, and to retain some of the older approaches that we think make sense. So we have struck a kind of middle ground on this stuff...we've taken the lessons from newer revenue streams that are tied to more progressive ideologies, and

> imported them into traditionally funded services."

The change in AHRC's self-image from a small, family-like, "conservative," organization to a larger and more progressive one was something that was managed in a self-conscious way as soon as the issues had been conceptualized.

> "I realized we were so traditional...so conservative and hide-bound that we were missing all these opportunities to do programs and exciting things, and a future that was colorful, interesting and growing. So we basically began to modify our strategic plan to bring in some newer kinds of programming, to convert some of our existing kinds of programs, and to reflect it all in a newsletter because it seemed to me that people would view us through the lens of our newsletter."

The newsletter is **The Chronicle**, regarded by many as the best newsletter produced by any mental retardation agency. (Several of my interviewees from outside the agency remarked about the quality of **The Chronicle**). The newsletter had been published by the agency for many years and was filled with birthday and anniversary announcements. Well before meeting Lou Brown, Goldfarb had discussed changing **The Chronicle** with the Board and they were amenable.

> "We began to look for a way of changing it. But also to change the agency. I thought we needed not only a more progressive image, but actually to become more progressive. So I used **The Chronicle** to create what was at the beginning an illusion or an image of growth, change and progressiveness...I knew that if we sold it, we would buy it from ourselves... I got somebody to do it, Shirley Berenstein, who was an educator here and had been the principal of one of our schools. And when I first saw it I realized that it was, you know, young, progressive and didn't feel like AHRC at all...the

> image that Shirley was presenting was progressive and contemporary. And it occurred to me that this would be a way for us to become that way, if we could live up to the image that **The Chronicle** created for us...and that is exactly what happened...We've become the agency that **The Chronicle** is all about. So I would say appearance preceded, and influenced, reality."

By the time Lou Brown visited AHRC, the agency was already changing how it was thinking about itself. The Brown presentation solidified what **The Chronicle** had already been promoting.

The management structure of the agency also needed to change to accommodate growth. When he first arrived at AHRC, the Executive Director was basically involved in all core administrative functions and activities. This was the gemeinschaft tradition of the agency. This would have to change if the agency was to become more progressive and larger. Then Goldfarb hired Bob Gundersen to put new management structures into place. Goldfarb comments,

> "As we grew larger, I moved further away from hands-on [management] and since we are a decentralized agency in terms of small, scattered programs, it's important. It's impossible to be in touch with everybody. You become more dependent on your subordinates...you have to confer more authority to people in key positions...and it doesn't matter that you don't hear all about the details because philosophy will be more internalized by the staff and therefore the product is better even if you don't hear every detail of every interaction...So...what I did was to delegate an enormous amount of authority and encourage my subordinates to do the same. And to depend upon groupings of people at the same level to make critical recommendations and decisions about the operations of the agency..[I tried] to take a lot of that out of my hands, which has driven me crazy because it was very hard for me to

> give it up. On the other hand, I know that the product is better so I can live with it."

Goldfarb developed a management philosophy that he describes as "home grown." As the agency grew, he developed a management team that reflected what he feels is a style of management that allows individual managers to manage in their own way, ("I think that management style is probably better when it's idiosyncratic rather than institutional.") Here is Goldfarb's characterization of AHRC's management.

> "We...don't write administrative memoranda and we don't have regular administrative meetings by design because regular cabinet meetings can become a kind of...800 pound gorilla, and you spend your time finding enough food to feed it...it's useless. So we do most of our administration en passant, as it were, in a very fluid setting. If we need to talk about the relationship between the clinic and a residence, that meeting takes place."

In actuality this en passant approach to administration today is made possible by the administrative structures that were put into place beginning in the mid-1980's and have been on-going since Goldfarb hired Gundersen in 1984. Gundersen brought an administrative background in the non-profit arena and had managed a successful non-profit computer organization that tracked all foster children in New York. He was introduced to AHRC through Maggie Ames of the Interagency Council in New York City. Gundersen recalls,

> AMICHAEL recognized that there was a gap. We were about a 13 million dollar organization. And we had all of the facilities operating autonomously and reporting directly to him. There was really no administrative structure here or support services or departments. He recognized the need but needed somebody to do it. So I came in at that point and all the

> administrative departments, except finance and fundraising, reported to me. And when the organization got bigger, we split that and Judy came in to do the program side. But at the time I came there was no personnel department. There was a very rudimentary fiscal operation. We did not have a public relations function, none of those departments that you need as you get bigger."

Gundersen proceeded in this fashion to put necessary Departments into place.

> "Setting up a personnel function was probably one of the most important early things that we did. We tried to codify those things that did exist... gathering past practice and all that... So piece by piece you have it. And you look around and all of a sudden you have a real fiscal department, a real human resources department, public relations, office management, and a property department ... There are still some things we don't have, that we are trying to get to... I think probably within a couple of years we are probably going to need our own security chief. Being in New York City the reality is we spend a lot of money on security... so there are things we certainly could and need to do better."

The professionalization and expansion of management structures and personnel is inevitable with the scale of growth AHRC has undergone, even though it is a relatively "lean" agency administratively.

There are some notable features in the way AHRC is currently managed. One is that it has no quality assurance director. Gundersen describes why.

> "We decided at one point to set up a QA Department. And we hired a Director and it was an utter disaster. You had this meddling person with no

> authority basically because the Departments ran the programs. And yet she was in charge of all the audits. It was a stupid system and yet I believe most agencies run that way. We gave the responsibility of QA back to the Department Heads and that is a big part of what they are evaluated on. And we have got wonderful audits. OMRDD last year did not even know how to write their evaluation it was so positive."

Another important feature of AHRC's management today is its very strong incident review system. Incident review at AHRC is time-consuming, and yet management has resisted opportunities to streamline the process. Partly this is because they see incident review as a way for the agency to responsibly protect persons in their programs. And partly because it provides the window into the everyday life of agency programs, and is critical to the agency's ability to fulfill its mission.

Goldfarb acknowledges that the current style of management requires consensus. The problem when you are dealing with equals is that everything has to emerge by consensus and when it doesn't he is sometimes called upon to act as an arbiter. This he regards as a shortcoming of his style, but one that is minimized by the actual management team members with whom he works, a team DeIasi characterized as "a great team."

In the conversations that I had with various members of the management team, all seemed to agree that the way the agency was managed "worked." Furthermore they all expressed pleasure in working at AHRC and felt that they were working at the best agency in New York City. Many believed AHRC continued to maintain the flavor of a personal, small agency, while allowing for a large operation to be run efficiently and humanely. They also stressed that keeping the agency this way would present a challenge in the future.

In the following two sections we will look at how AHRC looks to two sets of people, those they are serving at a residential complex on 30th Street in Manhattan, and then through the eyes of administrators who interface with the agency.

A Visit to the 30th Street Supported Apartment Complex

Another way to look at AHRC today is through the eyes of its program participants. For this reason I requested that I be allowed to visit a residential program and interview some residents. All the interviewees had known each other for a long time, having been the first arrivals at Fineson House in 1970, and having lived with each other at the 30th Street complex since.

There were five people participating in the interview. Seymour Gittelson, whom as previously mentioned, is a 79 year old who is still employed in the workshop, of his own choice, making leather bags. Seymour is a soft spoken and sensitive man, quite likable and sweet, melancholy, in a particular kind of way. Charles Weinstein was also at the table. Charles is 57 years old, wears thick glasses, is short and somewhat overweight, but also unusually vocal and erudite. He is a social fellow. Charles also works in the same workshop as Seymour. He absolutely loves rock and roll from the 1950's, and was most enlivened when recalling this part of his life. Charles also loves going on trips and eating out. The third man at the table was Irving Shulman. Irving, at 76, was self-announcedly the first person to live as a resident at Fineson House in 1970. (This was corroborated by others at the table). Irving came from a large Jewish family in Brooklyn. He remembers attending an "ungraded" class in the 1930s at P.S. 226 in Brooklyn. He recalled his mother dying in 1941, one month before Pearl Harbor.

Two truly lovely women were also at the table. Katie Greenblatt (who just celebrated her eightieth birthday) came to Fineson house in 1971, worked in the workshop and was extremely pleased to be living at the apartments. Katie also remembered her days in special classes, her mother dying when she was relatively young, and her sister taking her to Fineson House soon thereafter. The last member of the interview group was Gilda Lindenblatt, in some ways the most outspoken of the bunch. Gilda told us that she likes to collect jewelry from street sales, that she enjoys going out on trips and to movies and restaurants. She also works in the workshop making leather handbags. Gilda's interests include art, learning clerical skills, and attending the seniors and communication groups at the workshop. Each of these individuals were interesting in their own right, and probably could have a short monograph devoted to their lives. Each had stories to tell that were revealing of both who they were, and what AHRC had meant to them over the years.

Several of the interviewees recalled the early days when they lived with their families. Several told of the stigma that they experienced, particularly Gilda who was still bothered by those childhood experiences especially in front of her mother. Everyone in the group had attended special classes in school, "ungraded classes." Their experiences in such classes were mixed, with some remembering excellent teachers who came to their rescue when they were teased by other students, and others remembering being treated unfairly at school. Virtually everyone said that their families took good care of them when they were younger. Seymour was particularly emotional about his large family and how much he loved them and they him, and how sad he was that many of them had passed away.

They felt that while Fineson House was perhaps not everything they wanted in a residence as they got older, the supported apartment complex where they were now living, which was created to meet the needs of elderly residents, was fantastic. They had nothing but praise for AHRC at having gotten them out of Fineson and into the 30th Street supported apartment complex.

The most striking thing about the group was how close they were to one another, how much like an extended family they acted. No matter who was talking during the interview, the others around the table would chime in, correct memories that had faded over the years, and otherwise demonstrate that these people had lived a life together, to paraphrase the famous German sociologist Alfred Schutz, they had "grown old together." It was truly a family, in the way Judy DeIasi described the residence at 81st Street. In fact, I was so struck by how close they were, how much richer their lives were than elderly couples or individuals who lived on their own after a "normal life," that I commented to them about it. Irving's response was telling and representative, "Thank God."

The most impressive feature of my visit to 30th Street was that these elderly persons had one another in a kind of extended family, while many "normal" people of this age experience lives of loneliness and even desperation. In all honesty, I could not help thinking about my own old age, and what my own social situation would be when I was 79 and, like Irving, using a walkette to get around. Would I say, "Thank God" if someone asked me about my living circumstances?

The residents of 30th Street lived normal lives and referred to themselves as "normal people," and in some ways their life style was typical. They worked at the sheltered workshop during the week, and enjoyed weekends in the same way most working people do. All but Irving had chosen to continue to work in the workshop, even beyond retirement age. This is perhaps not exactly the norm. But in most ways the lives of the residents at 30th Street are indistinguishable from most other persons. When asked what they do with their free time we got the common answers, go to the movies, take walks around the City, go out to eat and the like. And, they determine their own schedules and activities, within the limits of reasonability and fairness to others.

Another thing that was remarkable about the group was their similarity to their parents. This was evident in at least two ways; in their strong sense of social responsibility, and in their friendly competitiveness with one another. The founding parents clearly had a concern for children with mental retardation that transcended their own personal circumstance. This was true of the residents of the 30th Street apartments whose concern for others with mental retardation was sincere and deep. This was most evident in the group's discussion of their self-advocacy activities.

Gilda: We advocate for ourselves on certain issues.

Interviewer: What kind of issues?

Charles: The issue is to get more money from the State to give to AHRC to run workshops in all five boroughs...get people out of the State Schools and into supported apartments, into workshops. To rehabilitate themselves... We want to do something to get them out of State Schools and into a home where they can really be watched and dressed decently. Believe me, I went up to one of these places and I did not like it...I mean it was degrading. Geraldo Rivera condemned State Schools. Get rid of them! No more! [group agrees strongly]

Gilda: We feel strongly about it. Absolutely!

The group was asked what they felt about children today versus when they grew up.

Charles: We would like to see them grow up...the way we are now. We would like to see them grow up in a good environment. We need a good environment. We need to get these kids back in workshops where they can live like us normal people. We want them to be the same way. Not to be sheltered away from other people.

Gilda: Like years ago parents would hide their kids in the closets. Now it is all in the open.

Charles: We should teach them to be self-reliant not grow up in a closet. What good is that going to do?

Gilda: They should live their lives to the most of their ability.

When asked if they felt people are still ashamed of their children with disabilities, the group responded with a collective, "No. No!" Irving contributed, "No they're better off now... at least they can try anyway."

In addition these persons argued among one another about "who was first" to do x or y, or to live in Fineson, or to transfer to this or that workshop. They were constantly correcting one another's memories about their mutual time line. When I noted this to Mike Goldfarb his comment was, I think, exactly correct, "Just like their parents." There was something humorous and lovely about how they squabbled. They were family, arguing in the ways that family members might, trying to establish the facts of their 'growing old together.'

The final question asked of the group was about their feelings towards AHRC.

"Gilda: I'll tell you truthfully because they did so much to get us these apartments and to get us out of Fineson House. I really have to applaud them for that. And you know they are doing this for us because of what we didn't get when we were younger. Now they are very big now...It grew over the years...

Charles: Without them... I don't know where we would be, believe me!"

Given the problems all of us face as we get older, the residents at the 30th Street apartment complex-- Gilda, Katherine, Seymour, Irving and Charles-- were living a relatively happy, healthy and independent life, and for them that is what AHRC means today.

AHRC in the Eyes of The System

> "It was interesting. When we hired a PR firm for our Fiftieth Anniversary celebration, they did a lot of research on us. They called a whole bunch of people to find out about us. They said we were the best kept secret in New York. They couldn't find people outside who knew about us, but from inside the field what came back was universally outstanding. They said you should be proud of who you are within the field."- Bob Gundersen

When the sociologist John Horton Cooley coined the term "the looking glass self," he was observing that the "self" or "personal identity" is largely a product of how one is seen by others. The same can be said about organizations and for this reason interviews about AHRC were conducted with significant actors in the New York State system. The interviewees were asked about their impressions of AHRC, both historically and today. Taken together their remarks constitute a view of AHRC's current reputation in the field.

The first interview was Marc Brandt, Director of the New York State ARC (NYSARC), who began his relationship with ARCs in 1971.

> "In those days AHRC was an agency that set direction in program philosophy and development. They were in the forefront. Today, almost thirty years later, they are the largest chapter of NYSARC, almost ten percent of the total organization. From the perspective of the Executive Director of the State Organization, they are not only the largest chapter but one of the better managed and better able to address the full and total needs of family members who have children and adults with mental retardation and developmental disabilities. So I look at it from our point of view as an

> exemplary chapter. And from the field's point of view, given our State, AHRC is always talked about in high esteem by everyone in the field. In the minds of many, ARCs are looked at as representing very traditional programs that were good in the olden days but today aren't. I think that the New York City chapter exemplifies traditional programs, but it also exemplifies the most current thinking in the field. Sometimes people lose sight of that, perhaps because they are big. But AHRC really offers the kinds of individualized and personalized options I think many of our younger consumers and family members are looking for. "

Brandt was very explicit in his appreciation of how AHRC's size has contributed to the overall quality of its programs.

> "I have never felt that increased size means decreased quality. Of course you lose direct oversight as you get bigger but on the other hand if you are innovative and remain true to the stated purposes of your organization, the larger you are the more you are able to try a lot of different things. You can offer your consumers a wider base of choices. You have many more options and can move people into different program models to meet their needs. I think that the city chapter is an example of a program that has grown constantly but has remained very, very true to its initial mission and purposes. It still has a very good handle on the day to day operation of its programs."

Finally, Brandt, as many of the interviewees, was clear in his appreciation of what has allowed AHRC to be the kind of agency that it has become.

> "One of the things that makes the city chapter what it is and has guided its growth over the past fifty years is that the parental involvement in governance remains exceptionally strong. Parental involvement on the Board in terms of

> matters of policy has allowed the city chapter to grow in the way it has, and yet remain true to its mission and purposes. "

Having read the history of AHRC Brandt's comments should not be surprising to the reader. In fact, his remarks are consistent with the basic view of all the interviewees, that AHRC is one of the top agencies in its field, and that what has allowed it to be a top agency is its combination of expertise and parental oversight.

Kathy Broderick

As a regional representative of the State Agency, Kathy Broderick of the Regional Office of the New York State Office of Mental Retardation and Developmental Disabilities worked closely with AHRC developing community services.

> AI=ve known about AHRC ever since I entered the field twenty years ago, but my personal knowledge of the organization began when I entered the community services unit at the New York City Regional Office about five years ago. I worked with AHRC in developing services for people with developmental disabilities living in the community and who had been waiting a very long time for services. I can only say that there are over two hundred agencies in New York City that serve in some capacity persons with developmental disabilities. And AHRC is by far one of the most knowledgeable, most dedicated and concrete agencies to work with. They have a unique personality with a Board started by parents and when you are dealing with parents who are looking out for the best interests of their children you get a different level of dedication. So that is what makes them partially unique, that the Board holds them accountable for the quality of the services, and how services are developed. They have a good sense of humor, which you need in this field. They can ride the bureaucracy and when

> you are operating and developing services for people with mental retardation and working for OMRDD I will be the first to admit there is bureaucracy. They work with it and they know when to fight and when to negotiate. Some of the agencies don't have that skill and they kind of miss the boat. "

I asked her whether AHRC is seen today as a progressive or conservative agency

> "I don't think in a system that takes care of people, that does human services, that there can be too much protectiveness. We take care of people and it is a lot easier to take care of a car. If it breaks down you fix it. If a person breaks down it is not quite as easy to fix him or her. So AHRC's protectiveness as it is known in the field today has only increased and improved the quality of services they provide. AHRC has taken a conservative stance about taking risk, believing in the **dignity** of risk, and they have provided the individual with choices, but choices from within reasonable and available options. They take the best of the old and new."

I questioned Broderick about her view of the relationship between AHRC and OMRDD in the future, especially if, as was proposed above, the Golden Age of Mental Retardation is a thing of the fiscal past.

> "Based on AHRC's expertise, their ability to manage well fiscally, in times of tight or restrictive funding, the cream will rise to the top. Those are the agencies that are going to survive and in the long run I only see the relationship between AHRC and OMRDD getting stronger. Some agencies that are smaller and do not provide good quality services may fail in time and those programs are then taken up by other agencies, and AHRC is typically one of the choices offered to the clients. Some of the smaller agencies that operate quality programs will survive though, with the help of OMRDD's

> program to strengthen the small provider. They will not all go away, nor should they. With the governor's new initiative, "New York Cares," I think AHRC will be a major contributor to its success. But there may be consumers who do not choose them, who might prefer a smaller provider in Bedford-Stuyvesant for example. But I believe that AHRC will be a major contributor, of course depending on how many people indicate their choice of them."

Broderick thus sees AHRC in the same kind of light as other interviewees, a large organization that marries technical expertise in management with the care and concern of a parent/family dominated Board. She clearly expresses some optimism about the future of the agency and its relationship with OMRDD, and this at a time when optimism in the field of developmental disabilities is quite hard to find.

Maggie Ames

Maggie Ames is the Executive Director of the Interagency Council (IAC) in New York City, an organization of metropolitan area providers of service to persons with developmental disabilities and their families. Coming out of a background in foster care, nursing homes and senior centers, when she became IAC Executive Director in 1983, Jack Gorelick was the Chairperson of the committee that hired her and he and Michael Goldfarb were the first agency professionals she met. AHRC was also the first agency with which she became familiar, as she put it "my introduction to the field." She comments on that period.

> "In 1983 everyone was in broad expansion. But in some respects the vision I had of them is quite similar to the vision I have of them today. They were much more business-like and much more entrepreneurial than you normally would see in human services. This is not unique to them, but they certainly are the epitome of it... But they are entrepreneurial not just to grow the

> agency, but because they want to meet the needs of specific people and families...It is very clear that they considered and still consider the consumers and the families they serve to be their responsibility. These are not just nameless, faceless clients. These are their clients. And that includes those in their services and those on the waiting list for their services. They take this business very personally. The parental influence has a lot to do with it. The family feeling in AHRC comes out loud and strong. And, they grew up without government money, which is not true of a lot of agencies in the DD field. There is a slight level of independence that AHRC exhibits that you don't necessarily see in other agencies. You know, it is like AHRC can say, 'Hey I have been doing this a long time before you came along and if you disappeared tomorrow I would keep on doing it.'

Ames remarked further about the current reputation of AHRC.

> "They are looked at as being very good quality, very family-oriented with a very clear sense of mission and values. And they are looked at as being incredibly strong, an agency that basically can do what it wants. Some agencies have a kind of love-hate-jealousy thing with AHRC. It is like, 'Look what these guys did. It isn't fair and I want it too.' But AHRC is known to everyone in the field as having this very clear organizational personality. A real strong organizational character; not flying all over the place or indecisive. It is their own agency culture and it has been very successful."

She also described the role of AHRC in the metropolitan area.

> "I think the AHRC culture has had a really significant impact on the field in general in the downstate area... Their approach to defining the way things ought to be has definitely had a great impact on their colleagues, there is no

question about it... Part of it is formal and part informal. It is clear that some of what AHRC is about is not only the organization but the charisma of its Executive Director, Michael Goldfarb. Back when I started it really had a lot to do with personalities, not agencies. It was Michael Goldfarb, Joel Levy, and Tom Cribbin, Ida Rappaport and Mickey Marlob basically who went to OMRDD in the late seventies and said they were not going to provide beds for persons coming out of institutions unless we can be given equal dollars for people who are at home and who never were institutionalized. These Executive Directors held each other to the promise of this commitment. If they had not stood together and protected people at home you would not have the community-based care system that you have in New York City today. And IAC grew out of that as well. They were politically so astute and had the backbone to insist on their way and stand with each other."

"Within the last five years AHRC has become an incredible breeding ground for leaders in the field. Their second level managers, the level right below Michael, are really top of the line and have done an incredible job. AHRC is an agency that will be around for a long time to come. Not only will they be around for a long time, they are going to be a core piece of the system for a long time to come. They are willing to think through the philosophical issues whereas other agencies are more concerned with what they can do to get into compliance. AHRC is more willing to think and ponder and they are leaders in that way as well. A tone is set, and some of it has to do with Goldfarb, that it is ok to question what you are doing. The management there is not in lock step. They are clearly allowed to question and disagree, although they seem to be in basic agreement about most things. It is because of these people that AHRC was able to get into professional management without losing the mom and pop flavor of the agency."

Ames' historical association with AHRC, and her position as the IAC Director, has allowed her to appreciate AHRC within the context of the growth of the field of developmental disabilities. While she acknowledged some other agencies had also managed to maintain the parental influence while expanding, none had done so to the degree, or with the success, of AHRC.

Thomas Maul

The last person I discussed AHRC with for this writing was Thomas Maul, Commissioner of New York State's Office of Mental Retardation and Developmental Disabilities (OMRDD). Maul joined the State agency twenty-five years ago and has been familiar with AHRC since then, during this period rising through the ranks to become the Commissioner of one of the largest state government agencies serving persons with developmental disabilities. Maul recalled that his boss when he arrived at OMRDD recommended that he contact AHRC and Michael Goldfarb, who had recently been hired as the Executive Director. He did so and was so impressed with Goldfarb and the agency that he began to appoint AHRC management to many committees and review panels.

> "Many people recognize that AHRC has had an impact on those they care for and their families. But they also have had an impact on the way services were developed in this state, especially Mike Goldfarb. I have called on them many times to assist me in statewide initiatives. And the parents too, people like Jerry Weingold. We really built our field upon those voices."

Commissioner Maul was very clear in his understanding of the mental retardation movement in New York State, assigning a central role to parents in helping to forge the way, with the state government and professionals often responding and building upon parents ideas. He also appreciated that what makes the field of developmental disabilities unique, and his state agency unique, is the relatively high degree of parental involvement. He looks to agencies like AHRC as a way to correct mistakes made by government. "You know, bureaucracies can always go astray but if you have parent involvement they are going to keep you on track." Maul sees this as the great strength of AHRC, that it has been able to expand and become a large bureaucracy without losing the oversight and input of parents. What he feels "what makes AHRC a great agency is that despite its size it continues to focus on the individual, individualized supports and individualized programs." He was also, however, aware of the problems that agencies like AHRC have in maintaining this high degree of parental input from the younger parents today.

I asked Commissioner Maul to be candid about his relationship with AHRC today. His response was telling. "Well, I'll be honest with you. Not only do I trust them, but many times I will take their advice." This remark corroborated what I had heard from many others during this project that AHRC has historically, and continues today, to be seen by OMRDD with the highest regard and looked to as a leader in the field.

When I asked Commissioner Maul about AHRC in the future he said that the agency would continue to play a major role in the expansion of services in the State, for example in the Governor's recently announced initiative to create residential beds for those on waiting lists and in the community. Maul was clear that this will mean a considerable amount of growth in New York City and that OMRDD relies on agencies like AHRC to enable quality services to expand. In his opinion, the long history of cooperation and mutual respect between AHRC and OMRDD will undoubtedly continue for a long time to come.

Taken in tandem, the remarks of Brandt, Broderick, Ames and Maul can be seen as a kind of snapshot of AHRC taken through the eyes of important figures in New York's human services system. Continuing with this metaphor, the snapshot appears in good focus. That is, there is considerable agreement about AHRC and what it represents as an organization in the field today. It enjoys a reputation equaled by no other agency in the state, partly because of its unique history and contribution to establishing the field. But its perceived prominence in the field is also because in its transition from small to large agency AHRC has continued to provide political leadership, been incredibly successful in entrepreneurial terms and remained faithful to the agency mission established by parents fifty years ago.

AHRC in the Twenty-First Century

While prediction is by nature an inexact science, and while many possible futures can transpire from any particular present, there are certain trends and issues that AHRC faces today and in the twenty-first century. One is a growing accountability in health care spending, Another is a shift in social welfare spending partially because of social conservatism regarding state funded supports and services.

AHRC has always been a family-governed agency. But in its early years, the family members were primarily parents. There is a current transition period in the leadership of AHRC that is basically due to the aging of the founding parents, many of whom are now in their 80's. In more recent years there have been attempts to recompose the Board with siblings and with younger parents. The expanded concept of family and the inclusion of siblings on the Board has proven very successful. The current president of AHRC at the time of this writing, Dr. Marilyn Jaffe-Ruiz, is a sibling and the sibling committee of the Board is very active in networking with other siblings and disseminating information. The attempted recruitment of younger parents, to be discussed further below, has proven to be somewhat more problematic.

Board member and parent I. William Stone when asked about the worst-case scenario for AHRC in the future said,

> "The worst case probably would be that we become a totally professional organization. That the parents and siblings don't get involved that much, and this could be as much the fault of parents as AHRC... Parents think differently than professionals. This is my son and he is not the same as that person over there. Don't try and fit him into a hole or square... Parents keep professionals 'honest'... That is why AHRC is the best agency in the city."

Judy DeIasi discussed the recruitment of younger parents as AHRC Board members.

> "Why aren't the [younger] parents joining us? This becomes the discussion constantly at Board meetings. Michael and I try to tell them this is not the 1950's anymore."

And of course part of the answer is the different periods in history. We live in a much more hectic and faster paced society than in the 1940s. Further, political action and the belief that we need to dedicate ourselves to "making a better world," is much less a theme in everyday life today than after World War II. To the contrary, the experience of many who lived through post-World War II America are not at all that hopeful about a better world. They are, in fact, more concerned with maintaining the standard of living and quality of life that they have had in the past. At the time of this writing wealthy persons continue to make money at an amazing rate; yet the average working American has seen a serious erosion in his/her buying power in the last thirty years, and probably will continue to do so. This is the fiscal frame within which citizens have formed their modern apolitical conscience. At the same time the average American has lost faith, perhaps for good reason, in government and political activity during this period. In sociological terms it makes sense that people under such conditions would be less likely to participate in voluntary political action.

DeIasi explained the many reasons why it is difficult to get younger parents involved. Some of them, many of them, are impoverished and contend with the serious problems prevalent in such environments. Those who are more affluent, tend to shop around for services from the various agencies to see where they can get the best deal. They do not perceive a need to serve the agency, since so many services and supports exist. To some degree, and this was a comment made by several of the founding parents during the interview, the younger parents today take for granted all the advocacy and political lobbying that the founding parents did. The younger parents, having their child in the "Golden Years" of mental retardation, do not understand what it meant to have been in Ann Greenberg's situation. Those of us in the field who are a bit older, and perhaps have had a chance to see and learn about the cyclic nature of history, see the lack of political participation by these parents as a serious problem to our field.

The fiscal and political climate facing the agency is also completely different than that when it was founded. It is clear that changing the world by creating institutions and public awareness, the basic idea of the founding parents, is no longer a viable strategy for agencies serving persons with mental retardation to follow. This has led to a more general strategy of opportunism and entrepreneurialism-- following the directions of public policy and using these to construct systems beneficial to the basic mission of the agency- providing for a good quality of life for people with mental retardation. In this sense AHRC is still seeking resources and expanding its operational base. But the fiscal and political climate within which this is occurring is not positive for people with severe disabilities.

Goldfarb comments about fiscal issues facing the agency.

> "An enormous amount of money has been spent on this field, and people are tired of it. And it has nothing to do with the state of the economy...I had this terrible fear eight or nine years ago when things started getting dicey and politicians were saying, 'You've got to learn to do more with less.' And academics were saying, 'It's time to move from center-based programming to natural supports,' which is another way of saying that you have to cut your budget...I always felt when people were saying, 'It's because the economy is in terrible shape.' [NB. New York City had a budget crisis in the 1980's] that was never the real reason. And I was right. Because now we have a situation where the economy is flourishing and they are still doing it...People in this field have always had the feeling they are doing the Lord's work and that people of conscience would provide. And the fact is they're just doing work, and nobody will provide if you are not careful. These days missionary or evangelical zeal will get you nowhere. People with disabilities are increasingly being seen as a burden, not as an opportunity to demonstrate charity. Now the question is why are we spending as much on a three year old with cerebral palsy as we do to send someone to Harvard...(ironically), what kind of investment is that?!...There is a sense today of weariness with caring for the weak."

The social conservatism is not only evident on the level of policy. It exists on the community level as well, as indicated by an increased resistance of Community Boards in considering proposals for new residences. The attitude is more negative than ever, with most Community Boards being unsympathetic and answering with "We already gave, go elsewhere." This change in values about people with disabilities is not only in the United States, it is a virtual world-wide movement. In my own travels, and this is corroborated by Susan Parker, Secretary General of Rehabilitation International, there is a mean-spirited social conservatism that is rearing its ugly head in all industrialized nations.

Despite this relatively grim scenario that would seem to indicate fiscal austerity for persons with complex and life-long needs, there is still agreement in the management team that AHRC must continue to grow in size. Gundersen comments,

> "I think a management maxim is, that as soon as you stop growing you go backwards. If you are growing it is always offering you ways of promoting good people and not losing them to the outside. We can always advance people in this organization. There is an esprit that builds when you are growing and when you are shrinking it turns into the obverse of that.... The complexity of what a large agency is able to do is so much greater than a small agency. I mean we can put something together overnight that a small agency simply wouldn't have the resources to do."

For agency management the question has become how to pursue the basic goal of AHRC, to enhance the quality of life of people with mental retardation and their families, while growing in a fiscal environment unfavorable to 'needy populations.'

In the United States fiscal conservatism has taken a political and economic form in the HMO movement. Goldfarb noted that an environment that forces agencies towards ever greater efficiency tends to weed out the smaller agencies, and favor the larger ones. While AHRC is a large agency, and while it has done relatively well in terms of aggressive fund raising and pursuing revenues, "it's a bad environment." Goldfarb puts it simply when he says,

> "Managed care is nothing more than an expression of the unwillingness to pay lots of money for human services... based upon the decision that we pay too much damned money for health care. Now I don't know what is too much

> or too little, but the premise is that we spend too much."

While managed care through Health Maintenance Organizations has become huge business in the US, people with chronic disabling conditions have been mostly exempt from its provisions. The management team had two major concerns should this change. Speaking about managed care companies and disabilities Goldfarb said,

> "If they ever get their act right and take a case management, cost-reduction approach to long-term care for the disabled, they'll put...this industry right out of business. Because their approach will be, 'cure them or discharge them,' and we don't do that... We're involved in enriching people's lives, enhancing their potential and maintaining their capacity to function. And that is not something that managed care systems want to pay for."

But managed care companies are not the only threat on the horizon to agencies like AHRC. There is also currently a huge growth of private companies on a national scale that are more sophisticated than most agency providers and are moving aggressively into states by underbidding the existing providers. Goldfarb comments.

> "Because of their size, because of their scope, they have the ability to market better than we do. They have the ability to be more efficient than we are. And, they are moving aggressively state-by-state and underbidding existing providers. Now, how do I underbid a national proprietary corporation? How do I go to my Board and say, 'I'm cutting the price on this product by ten percent. I have to take half of my "overnight" [coverage] away. Agencies like ours that are driven by family values have a very hard time pricing themselves to compete in that kind of market place."

The managed care situation and the expansion of large national proprietaries has led members of the management team to think creatively about obtaining revenues for the agency in the future. One idea that is currently being tested is operating generic services such as community health clinics, and serving the population of persons with mental retardation within these generic service programs. Funding for certain social programs such as day care for children, home health care, nursing home care, and so on has remained relatively strong when compared to that of special interest groups such as persons with disabilities. The idea of growing into social service areas that social policy seems to favor has thus become one strategy of management. Goldfarb describes getting the agency deeper into day care.

> "I want to use it as a way of getting us deeper into day care; day care for kids who are disabled and who are not disabled...If we could use a social problem and public policy shift tied to new resources to provide integrated services that include disabled people, that to me is the future of the agency."

A challenge in this kind of program development will be keeping AHRC's focus on its original mission, to enhance the lives of people with mental retardation and their families, but if AHRC falters financially and does not continue to exist, there will be no mission to which to be faithful. But, the opportunity for expanding the agency will exist if management is able to grow in ways that follow current social and institutional changes.

A whole set of issues is posed to the agency around the extended life expectancy for people with disabilities through development of medical treatment and care. When AHRC first began in the 1940's it was envisioned that children born with mental retardation would not survive their parents. Now it has become normal for the reverse. In addition the incidence of disability has not decreased, so we find as many persons with disabilities needing more care outside the home than ever before. There is likely to be a huge demand placed on the agency to care both for aging baby boomers who are themselves mentally retarded, as well as for the aging children of baby boomers with mental retardation who have remained at home. This coupling of epidemiologic and demographic trends will directly affect the future development of AHRC.

But growth will also occur within the traditional department structures, for example in those Departments concerned with adult services. There is general agreement that expansion in the area of adult services is going to be necessary. In the area of residential services this expansion has been managed by Gerry Maurer, who joined the agency in 1984. Maurer explained,

> "Basically I was brought on to expand and manage the [residential] department. We had 107 people living in the program, just a couple of supported apartments at that time and eight or nine group homes altogether. From '84 we're up to 363 people, with 27 houses, 54 apartments and with 30 more beds in development, which will add about 4 more houses. So we are getting close to 400. We have roughly quadrupled the program in fourteen years and have a budget of $20-22 million annually. And we were able to do this over a period when the economy was not as good as it had been in the 1970's. "

Maurer acknowledged that the future growth of residential services at AHRC will not resemble the previous fourteen years. Initially many of the beds were generated through close personal relationships with the state agency, and there was literally no formal process in place for allocation. That process has substantially changed. In addition, despite the recent (at the time of this writing) announcement by Governor Pataki for a five year plan of development for community services for persons with developmental disabilities, Maurer expressed that community boards today feel "that the community is saturated" and they are no longer willing to cooperate with the opening of community residences. The reasons for not cooperating have changed over the years, but the anger at the community board meetings is as bad, or even worse, than it has ever been. Maurer says that almost all community residences get approved anyway, either by the community board after a lot of education and coaxing, or by the Commissioner of OMRDD. But he is not sure how powerful community reaction to the new residential initiative might play out.

Maurer is however confident about the growth of a different part of services under his oversight, home care services.

> "We did form a home care agency ... a licensed home care agency a couple of years ago. We'd probably prefer to do a certified agency, which would bill Medicare and Medicaid directly but there's moratorium on the approval of those projects. So, we'll ease our way into the genre, to the licensed area, and provide home health aide services that will serve everyone but will focus on people with mental retardation and developmental disabilities. That's getting us out there as a general provider of health care services, at least conceptually. It's growing slowly but it's ... it needs a couple of years to percolate and I think it's going to take off."

In order to both expand and remain, at least in spirit, a gemeinschaft-like organization will present tremendous challenges to the organization. The problem of the continued infusion of family values into the organization has already been discussed in terms of the Board, but will probably in the future need to be addressed on a program level, not only 'at the top,' so to speak. The continued infusion of family values in AHRC will allow the management team to expand services in a way that will not result in diminution of quality of services. AHRC's commitment is that the agency, no matter how large, will do what it must to remain true to the original mission.

Fiscal management of AHRC will be enhanced through expertise and technology.

> "The size of the management will have to grow in the next ten years as we grow, and is subject to a lot of discussion. We will need to get more sophisticated in the financial area. To manage the kinds of monies that we are now managing, we are finding that our relationships with banks are getting infinitely more complex. They are more willing to lend us money, and they are getting smarter too."

AHRC is installing new computer technology that will present the possibility of both preserving agency culture and addressing certain key agency functions such as cost containment and billing, functions that need to be upgraded as the agency continues to grow. As Board member I. William Stone put it, "With regard to computer technology, we must go into the 21st Century. We are a $100 million organization. If we don't keep pace with technology, we are just going to lose it."

A critical issue facing AHRC and other human service agencies in the 21st century will be maintaining high caliber direct care personnel. In almost all urban areas in the US there are increasing problems in securing and keeping a well-trained direct care workforce. Despite its relative success in this area AHRC still faces this problem. Managers at AHRC understand that the quality of life of people in their programs is directly related to the quality of the work life of their direct care personnel. The agency has thus far done an exceptional job in recruiting and maintaining a high quality direct care workforce, especially given the fiscal climate and resources within which it operates. Personnel recruitment and development will continue to present a critical area of focus for agency management in the future.

Finally, in the future there will likely be an increased focus on the agency's public and political relations. Current management has hired an external public relations firm to help enhance AHRC's image and public visibility. These efforts will be linked to increasing public awareness of disability issues.

Conclusion

It is difficult to create a fitting end to this 50th anniversary history of AHRC. One cannot help but be impressed, even in a brief document such as this, by the incredible variety of human experience, both individually and collectively, that the phrase 'the 50th anniversary history of AHRC' glosses. No words can do justice to these human stories and efforts that constitute the reality of AHRC's history-- a history that spans literally from one world into another in terms of the treatment of people with mental retardation. And as these pages have indicated, AHRC itself was one of the prime motivators in this incredible reversal of policy and practice; in retrospect an almost unbelievable accomplishment.

It is said that history is driven forward by both the great forces of economics and the power of ideas. In considering the possibilities for AHRC, the economic and ideological future of America is so unsteady that it is literally impossible to predict what it will look like in one year let alone twenty or thirty. Certainly AHRC faces many fiscal and ideological challenges as it enters the twenty-first century. The society of the Golden Age of Mental Retardation, a society of their making, is a thing of the past. Yet, as this story indicates, history is always made by people and it has a way of calling forth what is required from us. One can hope, and with some reason for optimism, that the same fervor that characterized the founding of AHRC will again emerge in its future family leaders. This will be the key to AHRC remaining the kind of organization it has always been, an organization driven by family values and concerns.

But, whatever the future holds for the Association for the Help of Retarded Children, this chronicler of its story is convinced of two things. First that AHRC has always been and will continue to be a leader in the field for many years to come. And second that it will be the social conscience and personal dedication of AHRC's program participants, parents, siblings, staff and administration that will create the substance of its future and enable the AHRC of the 21st century to "build a better world."

END NOTES

1- Inclusion refers to an educational model for children with disabilities that emphasizes their full participation in same chronological age classrooms whatever the child with disabilities' academic level. This model is distinct from main-streaming, in which children with disabilities participate in separate classroom in a school but join regular classes in those subjects in which they are on grade level.

2- The article titled "**Not Like OTHER Children**" is remarkable in several respects. First, that the mother wanted to remain anonymous, and yet the article is simply a beautiful exposition of her and her husbands efforts to educate their "feeble-minded" son. Yet her shame was so great that she would not sign her name to the piece. Even more stunning and indicative of the thinking of that time was her conclusion. After telling about all the hardships and efforts they made to physically and mentally stimulate their son she writes, "We know that the hardest part of all is yet to come. For if we ever have other children, we must make provisions to have our 'different' little boy live away from home. It is too bitterly unfair to let a normal child face the pity, the curiosity, the whisperings about a defective child that we, as adults, find it hard to meet. Then too we know that our handicapped child would be miserable if he had to compete, though it might only be in the playground, with normal children. He has the right to be among his own kind, where he need face no unfair competition. Only so can he possibly be happy as he grows older. Anyone who doubts this need only think back to his own childhood, to remember with shame how heartlessly the neighborhood idiot was teased. Those are plain words but this is a situation that calls for plain thinking...We may gloss over the facts but the world won't. The time will come when it will be best for our child to go to a special institution." The mother then goes on to lament how her son will always be in their hearts and minds, even though they will not be able to help him any further. It is quite striking to me that a parent such as the one that wrote this article, who was clearly devoted to helping her son, was so universally surrounded by such negative attitudes that she herself had come to accept them as natural. The article illustrates how deep the stigma and shame of retarded children was during this time in history, and how it was an inescapable fact of life for even the most devoted of parents.

3 - I take this remark to refer to Ann's eventual understanding that all parents of children with mental retardation share certain common experiences, whatever their decisions about the welfare of their family.

4 - The role of chance in the development of the parents' movement and mental retardation should not be underestimated. Gunnar Dybwad, Executive Director of the National Association of Retarded Children in the 50's and 60's tells the following story about the mental retardation movement on the Federal level. A similar event occurred in 1955, when Arthur Trudeau, wealthy businessman and parent of a child with mental retardation, happened to meet John Fogarty who was then head of the House Sub-Committee on Appropriations for Health and Human Services (making him one of the most powerful persons in this country with regard to children services). It happened that Trudeau knew Fogarty through his lobbying activities in Washington, and it happened that one Christmas evening in 1955, Trudeau was to bump into Fogarty as he was leaving work and invite him to a Christmas party. It was there that Fogarty was exposed to the plight of children with mental retardation and their families. In the next meeting of his sub-Committee he pushed hard for legislation on the federal level, and suggested the formation of a Congressional panel of experts on the topic, a precursor to the President's Panel that was to be created by President Kennedy in 1961. The Conklin-Weingold meeting and the Fogarty-Trudeau encounter both show how chance played a significant role in the development of the field.

5- The source for this document were the personal files of Gunnar Dybwad, housed in the Howe Library on the grounds of the Fernald School. The draft document appears in published form the next year in the American Journal on Mental Deficiency, Vol. 45: 326-328. The following briefly characterizes its provisions. Under "Institutional Care" there is a discussion of the extent, nature, administration of, specialized services in, and special study and control of state schools and hospitals. Mentioned under the heading "State Extra-institutional Care" is the need for intermediate care in addition to 'parole service' (ie, being released from an institution and under social supervision) such as hostels, family care, supervised clubs, standards for personnel (interestingly citing standards developed by the New York City Committee for Mental Hygiene) and the need to develop better relationships with organized labor to "effect vocational adjustment." Under the topic heading, "Education in Public Schools" there are recommendations with respect to extent ("ungraded or special classes" to meet the needs of about 1% of the school population), nature (programs should be set up to the capacities of each child and include social and occupational training), and after care (ie, the need for social services and vocational teachers to help youngsters find and keep employment). Under "Research" the document calls for broad research into the incidence, causes, treatment and social planning in each state. Then under "Coordination of Work" the document presents what is essentially a call for statewide planning that would coordinate all the state agencies necessary to address the problem of "defective adults and children." Finally, the document calls for, under the heading "Educational Work," education for professional groups (including institution staff, doctors, psychologists, clergy, teachers, social workers, nurses and staff of welfare agencies) and lay groups (including parents and foster-parents, the general public with regard to attitudes and making a "proper provision" and public officials as to the need for public expenditures.

6- This early participation of parents in the deliberations of AAMD on nomenclature change was substantiated in part by the personal files of Elizabeth Boggs housed at the Howe Library. The particular document mentioned is a blue mimeo sheet (1952) of the Nomenclature Committee, on which Elizabeth sat as an ex-officio member. She actually was a member of AAMD, having received membership, in her words, "before they kicked the parents out."

7- Mr. Harvey Pacht, of the Self-Advocacy Organization of New York State put these feelings into words very well, "Mental r, [he will not actually say the words 'mental retardation'- DG] we don't like those words. They were misused and misinterpreted by a lot of people. Especially children on the streets…Those words were used to dehumanize people and hurt them...People with disabilities cannot and never will be comfortable with those words...always associated with horrible things they remember in the past...It is like a cloth with a bad stain. No matter how many times you wash it, the stain will never come out."

8- In 1957 Alfred Katz received a Ph.D. degree from the New York School of Social Work with a dissertation titled, "An Investigation of Self-organized Groups of Parents and Relatives in the fields of Physical and Mental Handicap." This document is the source of this data.

9- Jerry Lewis' MS telethons are another example, although his portrayal of 'spastic' characters in the movies of this era had many parents of children with disabilities up in arms. Also, Danny Kaye's portrayal of a parent of a child with polio in the 1950's movie "The Five Pennies" is another example of the growth of media awareness of disability issues in the 1950's. In 1961, an episode of the television show "The Defenders" was devoted to the issue of physician euthanasia of a "Mongoloid" child.

10- It is interesting how a simple phrase such as 'pilot classes begun in 1951' can mask the human story to which it points. Devino Riandoto, an Italian immigrant without specific education in mental retardation, was the first teacher hired by AHRC and one of the interviewees for this project. Riondoto was actually hired in 1953 as the first full time AHRC staff teacher, and began teaching in the basement of a Jewish Synagogue in Brooklyn. He had eleven boys and twenty girls in his classroom, with no assistants. He remembered how parents had access to the class and that they were really his bosses. He 'learned on the job,' and given the nature of his job, a single teacher in a classroom of 31`'trainable' mentally retarded children, he quickly learned many lessons from his children. Riandoto recounted the pride with which he regarded his own work, in the face often of public ridicule ("And I stood it...in the school as well as on the street...I was proud...I walked straight up...I felt second to none.") He dealt with difficult behaviors ("As for difficult behaviors we had them...name it...You had to have a gold heart and a steel frame. A gold heart to feel that they are part of you. To a point strong to be able to cope physically...in a tantrum...you see these desks fly by..."). He described being a teacher to these children as requiring him to be "a man for all seasons," doing whatever it took to get the job done. He recalled the practical nature of much of his teaching, exposing his children to normal experiences, like shopping or going to Chinatown, or teaching them how to interact with one another. Riandoto described how he and his children built a strong respect and love for one another, how his last classes recently gave him a reunion, and I could feel how important that was to him. He never married or had children and to him his students are his children. Hearing him speak of his students one could feel his attachment to them. But hearing Devino describe his early experiences, to hear what it was like in those first classrooms, was overwhelming. I kept imagining to myself what it must have been to be alone in a classroom of 31 children with severe mental retardation, most of whom had never been to school before, with no training, and no one to help. No wonder he needed "a heart of gold and a steel frame." It is through people like Devino Riondoto that the educational aims of AHRC were given real form and reality. It is the everyday world that Riandoto and his students created in these classes that is the true story of

AHRC's early experiments in classroom education for trainable children.

11- In Elizabeth Boggs' files related to NARC, there is an entire folder devoted to "the New York Question" in which are found thirty letters (end of the 1950's) to and from NARC to AHRC and to The Welfare League and other institution groups, about various matters, but especially who should be the State's member to the NARC. There was bad blood in the air about this situation, and funding issues related to it.

12- The conflict between AHRC and the NARC, and then later the NYSARC and NARC, was due to many factors. Strong personality conflicts, perceived anti-Semitism, substantive differences on issues (for example, on the questions of whether ARCs should go into the provider business, and the role of workshops in the lives of people with mental retardation). In an interview with Gunnar Dybwad, Executive Director of NARC during the late 1950"s and 1960's, he remembered well the tension at national meetings between NARC, AHRC and other parent groups. He remembers the perception of the group as being "the Jews from New York City" and that Weingold was particularly argumentative and insistent that things be done his way. Dybwad, now 89, felt that Weingold resented Dybwad's appointment as Executive Director, and believed that he (Weingold) should have received that position. Whatever the actual case, one can feel the conflicts between AHRC and NARC had many levels to them.

13- The term 'developmental disabilities' began to be employed in the early 1970's and entered federal legislation in 1975. It is a legislative term, not a scientific or clinical one, and was invented to control entitlement to persons with disabilities. It is a functional definition of disability designed to ensure that only those with severe and (possibly) life-long disabilities get access to the most desirable funding streams.

14- In fact, exposés of conditions at New York state hospitals and schools, and investigations of 'incidents' within them have been part of newspaper coverage throughout this century.

15- As of this writing Ira Wohl's twenty year update of "Best Boy," called "Best Man," is awaiting release on Cinemax. This project was again done with the cooperation of AHRC and involving AHRC programs and staff.

16- The fact that Stone began to sensitize the agency to issues of accessibility so early on in the development of residential services created a tremendous number of beds within the agency that were located in wheelchair accessible residences. Gerry Maurer commented that AHRC probably has more accessible beds than any other New York City agency other than United Cerebral Palsy, which specializes in persons with physical disabilities. This great number of accessible beds presents unique opportunities to the agency at the time of this writing. Specifically, it allows AHRC to permit their residents to "age in place," as Gerry Maurer put it. This means that AHRC can provide home care services to persons in fully accessible environments who would otherwise face placement in a nursing home.

17- Today there are several national coalitions for the training of workers in mental retardation, one of which is sponsored by the Kennedy Foundation, the President's Committee on Mental Retardation and in cooperation with the American Association on Mental Retardation. Since the inception of the Goldfarb/Gorelick idea, the City University has also engaged in policy development, research and international exchange and development in the areas of worker training.

18- Goldfarb expressed a deep ambivalence about the current ideologies in services for persons with mental retardation. While acknowledging that some changes have been extremely beneficial (for example, the move away from institutions toward choice-driven support systems) others have been very negative. In fact, he felt that "..the origins of the current ideology are essentially a fabric of concepts and points of view not very much driven by empirical information, in which the mistrust of pre-existing service systems [such as AHRC] is the driving force, the vector." Further, the down side of the philosophies is that "a lot of the States have simply defended those programs because it became academically fashionable to do it. States closed their workshops and did not replace them with substantial or suitable alternatives." Thus, Goldfarb's argument with the academic ideologists in the field is not just a philosophical one, and his differences with their positions are not simply a matter of theory.

19- Thus Goldfarb remarked that in some ways the administration of AHRC today is as, or in some cases is even more, conservative than the Board. He cited the recent suggestion by the Board to Judy DeIasi that she shorten the incident review process that the agency employ and that she herself need not review in detail each case. She rejected the Board's advice.

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