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ABSTRACT

This report traces the recent recognition given to the needs and feelings of siblings of individuals with mental retardation. The development of social support groups for siblings from 1960 to the present is described, including the establishment of the landmark Brother-Sister Group, the founding of the Association for the Help of Retarded Children's (AHRC) Adult Sibling Support Group, and AHRC conferences on siblings of people with mental retardation and developmental disabilities. Literature written to address the problems of siblings of individuals with mental retardation is reviewed. The impact of several converging factors on sibling concerns is addressed, including the increased longevity of persons with mental retardation, the aging and death of parents who provided care, the closure of institutions, and the return to the community of institutionalized people. The fears and emotional conflicts of siblings of those with mental retardation are identified. Recommendations are made for a future agenda for sibling services that includes having all members of a family involved in future planning, starting services for siblings at an early age, and making genetic information and counseling available to help siblings make decisions about their own parenting. (Contains 15 references.) (CR)

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A Strong Sibling Network:

Forgotten Children No More

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Presented at the
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Why would a group of adults of various ages and backgrounds call themselves “forgotten children”?

Why would one of them use the ironic title “The ‘Discovery’ of Siblings” in a professional journal article?

Why would otherwise courteous, gentle siblings exile from their meeting a veteran professional who had organized the meeting, paid for the food, and given up much of a day usually devoted to his family?

A close look at the literature reveals that in the long history of mental retardation, at least in the United States, siblings were virtually invisible. It is only in the last half of the twentieth century that professionals began to pay attention to sibling issues.

In Scheerenberger's (1983) A History of Mental Retardation, which for all practical purposes ended with 1959, sibling is not listed in the index. A close reading of the text does not reveal a single reference to siblings.

In the preface to his second volume, Scheerenberger (1987, p. xiii) begins with “This volume covers the historical period of mental retardation from 1960 through 1984, 25 years replete with new concepts, new directions, and new aspirations”.

Again, there is no sibling listing in the index, but the text devotes a single but cogent paragraph to siblings.

“In addition to the parents, the needs of normal siblings were also recognized, and in 1967, the Association for Retarded Citizens of the United States started its Youth ARC movement, which in a decade had over 25,000 members who shared their experiences and difficulties and provided innumerable volunteer services. Throughout the years, other sibling groups were formed, for, the words of one young woman, (Hecht, 1983) 'Sibling groups and sibling networks are very important. Its hard to relate to someone you feel don't understand' (p.219).

Beginning in the late 1950's, the previously unexplored territory of siblings of persons with mental retardation, suddenly became worthy of attention by mental retardation professionals.

Farber (1959), in a landmark monograph, studied the effects of a severely retarded child on family integration. This study focused on the family as a unit and peaked interest in the needs of siblings.

In 1960, Meyer Schreiber, then director of group work and recreation at the New York City Association for the Help of Retarded Children received support from the United States Institutes for Mental Health to provide sibling services, as part of a grant to develop community resources and programs for persons with mental retardation and their families.

As part of this project, Schreiber established a guided discussion group for normal adolescents between the ages of 13 and 17 prepared to meet every 2 weeks to discuss their feelings about their retarded siblings.

This landmark sibling network, which its members called the Brother-Sister Group, met for 8 months under the leadership of a professional group worker. It was composed of 5 boys and 5 girls, mostly from lower middle class background.

Schreiber and Feeley (1965) concluded that the group experience helped the young people open up, to discuss family relationships, and to think more realistically about the future.

An important product of this group was the cooperative development of a powerful and effective pamphlet, "It's Tough to live with your retarded brother or sister". Schreiber, 1964).

This booklet, which is a summary of the group discussions, deals with telling friends about their retarded brother or sister, acceptance, helping the family cope, and activities the siblings do together. Over 200,000 copies have been distributed to date. It continues to be an effective piece of sibling literature.

Schreiber and Feeley (1965) concluded "Our experience suggests that the young person with positive family relationships is often capable of the emotional hurt and anxiety of having a retarded sibling without sever disruption of family and social life... The more clearly normal siblings of the mentally retarded can see the realities of their particular situation, the better position they are in to cope with them. This is the point of a group experience" (p.229).

The Schreiber-Feeley program had an important ripple effect. Many chapters of the New York State Association organized sibling groups, usually on a less structured basis. This pioneer effort had a strong impact not only on siblings directly involved but also on professionals, who had previously paid little attention to siblings and their problems.

"Siblings of the Retarded", the Schreiber and Feeley report, was featured in an attractive brochure by the National Association for Retarded Citizens made available to chapters throughout the United States. Its wide distribution did much to alert parents and professionals to the concerns of normal adolescents siblings of retarded children.

Unfortunately, after a few years the sibling effort in New York lost its prime advocate when Schreiber moved into the academic world. Without a gifted and dedicated leader, the adolescents involved could not succeed on their own. There would be a long hiatus before the Association in New York City would again respond to the needs of siblings.

Grossman (1972) insightful study of siblings brought further clarification of sibling issues. Importantly, he found that an older sister helped care for her retarded sibling during childhood.

Selma Miller (1974), herself a sibling, proposed that sibling relationships could be effectively neutral, and not necessarily more negative than among non-handicapped siblings There is less intimacy and admiration, but also less competition. Fortuitously, Miller, in 1982, would become one of the founding members of the AHRC Adult Sibling Support Group.

In 1976, AHRC received a license from the New York State Department of Mental Hygiene to operate a free-standing clinic, one of the first to provide clinical services outside a medical setting.

After 20 years with AHRC working in vocational training and adult day program, I was privileged to become the founding director of the clinic.

This was during a period of great turmoil in the field. In the 70's a series of federal lawsuits were beginning to spell the doom of large overcrowded institutions. In 1975, the Education for All Handicapped Children's Act became law in the United States. "Normalization" (Wolfensberger, 1972) was in the air.

Parent and professional organizations were demanding more normal, community centered lives for persons with mental retardation.

It would be comforting to be able to report that I had the foresight to realize that in these rapidly changing circumstances the role of siblings would take on a new significance. But the truth is that over the years we focused almost exclusively on the urgent needs of our parents and their handicapped children. Yes, we dutifully recorded the names of siblings in our clinical charts, but rarely directly considered their needs in our service plans.

After Blatt and Kaplan's (1966) Christmas in Purgatory, and the televised expose in 1972 of Willowbrook State School in New York by Geraldo Rivera, all hopes of reforming the state institutions had evaporated. For many years, with all their deficits, institutions served as a safety valve for families when there were no other options.

Featherstone's (1980), A Difference in the Family, a widely popular book in paperback as well as in hard cover, brought front and center the impact of disability on all members of the family. Throughout the book, she emphasized the important role of siblings and the need to give attention to their concerns.

By the late 70's, these factors converged to force us to pay attention to sibling concerns: (1) increased longevity of persons with mental retardation; (2) aging and death of parents who provided care for the vast majority who lived at home; (3) the closure of institutions; (4) the return to the community of thousands of institutionalized persons.

Within a few years, clinical staff were confronted by adult siblings who demanded help in resolving family problems that were impacting on their lives.

Forced to focus on those who called themselves "forgotten children", we found it useful to develop the following groupings:

1. The death bed vow: Many siblings, often literally at the death bed, had vowed to provide life-time care for their brother or sister. But they were having difficulty in fulfilling this pledge, and needed help in resolving their feelings of guilt.

2. It's women's work: Overwhelmingly, sisters were expected to accept sibling responsibilities. Brothers were usually exempted, except when they were the only other sibling. Only about 20% of those who came for help were males.

3. Miles from home or a phone call away: As we began to follow a family systems approach, we found a bi-model distribution of the geographical location of siblings. We found a large minority - perhaps 30% - who moved as far away as possible from their handicapped sibling. Others, usually female, felt they had an obligation to live nearby in case of incapacity or death of the parent caregiver.

4. Choosing a career in human services: An impressive number of siblings, we found have chosen to work in human services; many in the field of mental retardation. Others with other disabled populations; mentally ill, physically handicapped. Here there was a more equal balance of males and females. Many of these siblings are excellent psychologists, social workers, teachers, nurses, and direct care workers.

In January, 1983, AHRC and Hunter College co-sponsored the First Annual New York City Conference on Siblings of the Mentally Retarded and Developmentally Disabled. When 300 people came, in spite of the coldest weather in a decade, we knew that we had struck a raw nerve that would transform relationships between siblings and professionals.

The professional keynote speaker was Dr. Meyer Schreiber, now at Kean College, New Jersey, who provided a historical perspective and discussed his pioneer sibling project at AHRC.

The sibling keynote speaker was Marilyn Jaffe-Ruiz of Pace University, New York City who spoke of the sibling as advocate and issued a challenge to professionals to do more to meet the needs of siblings. Dr. Jaffe-Ruiz was also a founding member of the AHRC Adult Sibling Support Group.

Many adult siblings spoke openly and bitterly of the problem they experienced as "forgotten children". They attacked professionals for ignoring them and complained about parents who had been unmindful of their needs. The power of the siblings complaints had a strong impact on the professionals and parents.

This event marked the "rediscovery" of siblings by AHRC, and a commitment by the Association to develop a forum for siblings. The Board of Directors provided the funding for The First Annual National Seminar on Siblings of Mentally Retarded and Developmentally Disabled Persons.

This two-day meeting was held at New York University on May 19-20, and was co-sponsored by Kean College of New Jersey and New York University.

Siblings and professionals from all parts of the United States attended and enthuiasticly supported the call for greater interest in sibling issues and the expanded services for siblings.

Many siblings far distant from New York City reported that they had come at their own expense because it was the first opportunity for them to meet other siblings and to speak openly of their experiences.

Jaffe-Ruiz, (1984) a sibling as well as an academic, presented "A Family System Look at the Developmentally Disabled". She called attention to the effect on siblings of the developmentally disabled and the importance of involving them when considering family needs.

The two-days of discussions and confrontation had a cathartic effect on the siblings, parents and professionals and led to a determination to organize an array of services for siblings.

In October 1983, at the annual convention of the New York State Association for Retarded Children, AHRC siblings made a presentation entitles, "The Need for a State Sibling Network".

This presentation, attended overwhelmingly by parents, had a powerful impact on the convention. Many of them were shocked by the candor of the presenters and wept openly at the realization that they had often neglected the needs of their other children.

In December, 1982, the AHRC Adult Sibling Support Group held its first open meeting.

It was on that occasion that I learned a hard lesson about siblings. As I usually do, when hosting special meetings, I arrived at the office early; laid out snacks and arranged the room. About 30 siblings came to the initial meeting. They ranged in age from about 20 to about 50, and were overwhelmingly female.

About half were college graduates, and many were professionals with advanced degrees. They were intelligent, confident and successful in their working lives.

It was my intention to be the facilitator for the group and to attend and participate in the meetings. After calling the meeting to order and delivering some brief remarks about the goals of the AHRC Adult Sibling Support Group, I was politely but firmly asked to leave. The siblings had decided almost by osmosis, that their meetings would be for siblings only and unfortunately, I did not qualify for admission.

It did not enhance my self-esteem to be barred from a meeting I had organized, after overcoming the inertia and doubts of many members of the board of directors. I had assumed that after more than 20 years of service in the field, I had earned my credentials and the right to expect full acceptance by family members.

However, I had to painfully relearn a lesson that I had been taught silently in my work with parents. Families affected by mental retardation are members of an "exclusive club" that they have not chosen to join. But they are bonded together by experiences that outsiders no matter how well-meaning or sympathetic can never fully understand.

On that day, I learned that adult siblings needed each other much more than they needed "outsiders" whether professionals or parents. All they wanted from me was a place to meet, a few amenities and some clerical support.

I found that I had a significant but not sufficient role as an initiator of the sibling support group. It took me a long time to understand and accept the wisdom of their exclusiveness. But the results speak for themselves. The AHRC

Adult Sibling Support Group is now in its 14 th year and is probably the longest running adult support group of its kind in the United States.

The adult sibling support group meets each month to provide self-help peer support. Over 400 siblings are on the active mailing list. The group averages about 25 participants at its monthly meetings, primarily females. Often newcomers come for support and assistance who have never previously discussed their concerns with anyone.

The meetings are informal and open-ended. Members are free to discuss any issue that is troubling them. These include relationships with parents and other family members, personal relationships, friendships and planning for the future. They know that they receive from their peers a compassionate hearing. Often knowledgeable members can provide useful information that helps them solve their personal dilemmas.

Over the years, a core group of intelligent and dedicated siblings has remained active and serves as the institutional memory of the sibling network. They have been the catalyst for significant change within the organization.

The dynamics of the sibling group had an energizing effect on a parent organization that was reaching its maturity. With the support of the board of directors, AHRC applied for and received a three year grant from the New York State Developmental Disabilities Planning Commission to strengthen and expand sibling services.

The three year grant award in 1984, had the following objectives:

1- Establish an AHRC Office of Sibling Services, with a full time coordinator

2- Do outreach through a newsletter and conferences.

3- Provide counseling and system advocacy.

4- Develop a Sibling Resource Center

5- Develop a state-wide New York State ARC Sibling Network and assist other agencies in developing sibling support services.

Kathryn Edmundson (1985), also a founding member, used its ironical title "The 'Discovery' of Siblings" in a guest editorial in Mental Retardation. She noted that "Sibling resentment and anger at professionals is striking." (p.50) . She deplored professional ignorance of sibling needs and emphasized the need to regard sibling issues over the long term and not as a passing fad. This paper was widely distributed throughout the state and also served to strengthen the sibling cause.

At the Annual Meeting of the American Association on Mental Deficiency in 1985, the sibling support group, with myself as moderator, made one of the first of several presentations at state and national conferences.

In the presentation, "Inalienable Rights of Siblings", they pointed out that in the field there was acceptance of the rights of persons with mental retardation and also their parents, but siblings were regarded as individuals who had responsibilities but few rights. They called upon professionals to give them equal rights.

In 1985 and 1986, the New York City Chapter and the State Association co-sponsored the First Annual New York State Conference on Siblings and the Second Annual New York City Conference on Siblings. Both were well attended and helped expand sibling services throughout the state.

At its annual meeting in June, 1985, AHRC amended its by-laws to include the Sibling Committee as one of its standing committees. The Sibling Committee, composed of equal numbers of siblings and parents, was formed to foster the interests of siblings and make recommendation to the Board of Directors.

At the NYSARC annual conventions, a few months later, a resolution to establish a standing Sibling Committee in all chapters was passed unanimously.

Adult siblings are prime supporters of services for younger siblings. They speak sorrowfully of the isolation and confusion they experienced in their younger years and wish that they had been able to meet and socialize with other siblings.

Sibling groups for children and adolescents were formed which were patterned after the early work of Schreiber and Feeley. However, now the adult sibling group was available to provide personal and experiential support to these renewed efforts. With the establishment of an office of Sibling Services and a full-time sibling coordinator, child and adolescent sibling groups, initiated in 1985, have continued to this date.

Since 1985, under the editorship of Bonnie Cohen, a social worker, the adult siblings have published a newsletter for young siblings: Forget-Me-Not. This is a chatty, informal child-centered newsletter, much of it written by young siblings: a voice and a vehicle of free expression of their feelings.

One of the most delicate and private issues for adult siblings is their concerns about marriage and having children. The adult sibling support group offers siblings an opportunity to discuss marriage and parenthood in a setting where they were able to openly express thoughts and feelings they have never been able to speak of openly.

Members often express fear of a genetic problem: The possibility that they may have a child with a disability impacts on their future plans. Genetic counselors and researchers from the New York State Institute for Basic Research in Developmental Disabilities have provided up to date information to siblings at conferences and sibling meetings. As a result, many siblings have taken advantage of the genetic testing and genetic counseling services that are available, usually at no charge.

Bonnie Cohen's (1985) article "Good News - Genetic Counseling" expressed the emotional conflict involved in genetic testing, and the welcome result she received. She encouraged others to use genetic services rather than live with an anxiety that may not be warranted.

In 1986, the AHRC sibling effort was in full stride. Panel presentations were made at the annual meeting of the American Association on Mental Deficiency in May; in September at Region X of AAMD, and in November at the New York State AAMD.

In the area of governance an important breakthrough was made as a result of sibling activities. Three founding members of the Adult Sibling Support Group were elected to the AHRC Board of Directors. This vote of confidence in the sibling effort marked the beginning of a significant shift in the power structure of the chapter.

Although siblings were a small minority on the board, their presence created an important psychological shift: from a parent organization to a family organization. This shift was much more than semantical; it marked a shift from a parent centered organization to one that centered on the family as a dynamic unit.

For example: Parent Education meetings that were an important informational tradition became Family Education meetings. Parents Day, an annual all-day event that attracted hundreds of parents and their handicapped children became Family Day and attracted large numbers of siblings of all ages.

In 1988, our sibling effort was presented at the meeting of the International Association for the Scientific Study of Mental Deficiency in Dublin. I presided at a panel consisting of two siblings, and a parent who was a strong supporter of sibling activities.

The success of the sibling effort has had a strong impact on the membership and especially the remaining doubters on the Board of Directors. The external funding for the program expired in 1988 and the leadership was faced with a decision of whether or not to continue funding the program. The support generated from within the agency led to a favorable decision: continued financial support for sibling services.

In the 1990's the program has continued to provide established services and began to grapple with new problems that require new solutions.

In 1995, the chapter at the initiative of the Sibling Committee, held a two-day program to review its progress and to plan for the future.

On the first day, Donald J. Meyer (1994) directed a Sibshop, a workshop for siblings. Young siblings and adult siblings interacted in this unique workshop, which provides support and information in recreational atmosphere. In addition, direct care workers, professionals, and parents attended.

The fact that Sibshops and others is funded by the United States Department of Health and Human Services as a Special Project of Regional and

National Significance demonstrates the success of the sibling movement in recent years.

On the second day, a city-wide conference was held at Pace University entitled: Brothers and Sisters: A Lifelong Connection" with over 300 siblings, parents, and professionals attending.

Donald Meyer delivered the keynote address in which he lauded the efforts of the AHRC Sibling Program and challenged them to do more in the future.

The following workshops were presented: (1) For Teens Only; (2) For Parents of Young Children; (3) Making Long Term Plans: Guardianship and Financial Planning; (4) Genetics and Prevention.

The conference also initiated scholarship awards for sibling study or travel to conferences. My wife and I established the Jack Gorelick Sibling Scholarships as a tribute to the commitment so many siblings are making to advance the quality of life of persons with mental retardation.

Two awards of $1,000 are given annually to applicants selected by the AHRC Sibling Committee. The first recipients were direct care workers pursuing undergraduate degrees, with concentrations in mental retardation.

In 1996, one of the awards was given to a sibling for travel to the meeting of the International Association for the Scientific Study of Intellectual Disability in Helsinki, Finland, where she will deliver a paper " The Sibling: A Lifelong Journey of Care" Guthrie and Liska (1996).

For many years, siblings have maintained that they will have achieved full acceptance when one of them is elected by the membership to the presidency of the chapter.

On June 13, 1996, Marilyn Jaffe-Ruiz, one of the founders of the AHRC Adult Sibling Support Group, was elected president. After 47 years, the New York City Association for the Help of Retarded Children, one of the largest voluntary agencies in the country, elected a sibling. This historic event will undoubtedly have a positive impact on the future of the sibling movement.

From a historical perspective, we can see that in a relatively brief period siblings of persons with developmental disabilities have been "discovered", and in our particular care, "rediscovered" after a lapse of more than a decade.

However, in recent years sibling issues have become so insistent that they can no longer be ignored. In New York City, adult siblings articulated their needs to clinicians in an active parent organization and demanded assistance.

We learned that many siblings, justly, distrust and resent professionals because they tend to view siblings as pathological. We learned that siblings feel isolated and their greatest need is to talk to other siblings. Professionals will find that they can regain respect and trust when they prove that they are sincerely attempting to understand siblings and their needs.

Siblings have provided us with an agenda for the future:

1. All members of a family must be involved in future planning.
2. Services for siblings should start at an early age.
3. Brothers as well as sisters should have equal sibling responsibilities.
4. Genetic information and counseling should be available to help siblings make realistic decisions about parenting.
5. Outreach should be done to reach minority groups.

6. Adult siblings are often faced with "double trouble": the infirm parent as well as the aging brother or sister.

7. Siblings have earned the right to participate in all aspects of governance, including the highest offices.

As for myself, in 40 years with AHRC, I have found working with adult siblings to be the most difficult, and frustrating challenge of my career, but also the most rewarding. I have learned that mental retardationists need to learn modesty, and we have much to be modest about.

After all, we are the folks who too often blamed the victims. We regarded parents and siblings as pathological because of the tragedy of mental retardation. We, too often, viewed retarded people as essentially hopeless. We often supported the exclusion of "uneducable" retarded children from public education.

We are the professionals who established the large state institutions to "protect" society from persons with mental retardation.

Although in aggregate, we have done much in recent years to right our wrongs, we must never forget the dismal recent past. Including our almost total neglect until recently of siblings.

However, in the past two decades the profession has begun to gain the respect of siblings by acknowledging their unique position in the family. Sibling support groups, for children as well as adults have helped. Conferences by and for siblings have given them a voice. Presentations at national and international conferences have allowed siblings to speak for themselves. The Sibling Information Bulletin, Sibshops and most recently SibNet on the Internet/World Wide Web, are all valuable tools in overcoming the stigma of neglect.

I have, I hope, overcome the disappointment and rancor of being excluded from a meeting that I had set-up, on my day off. I learned on that day that an adult sibling group needed a facilitator who was also a sibling and that sibling activities will be most successful when the staff professional is a sibling.

I was delighted when, at her installation as president of AHRC, Marilyn Jaffe-Ruiz said she was going to appoint me a member of the Sibling Committee, which is responsible to the Board of Directors for all sibling activities. She designated me an "honorary sibling". That is honor enough for me.

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