



MASSACHUSETTS ASSOCIATION for RETARDED CHILDREN, Inc.

The 60's: Parents Find Their Voice Through The Arc Government Begins to Take Notice

When Billy was six-years-old we brought him to the Lexington Public Schools. They said, "Bring him back next year, we have nothing for him..." That basically said, "See you later." I enrolled him at Cardinal Cushing but realized how much there was to do to create a future for him.

Gunnar Dybwad told us about what was happening both in the United States and in other countries. He introduced me to Peter Goldmark, who was in the Sargent administration. In no time, I was visiting Nebraska with Jessie Sargent and then on to Sweden. We started 500 miles north of Stockholm and moved south. We looked at day and work programs, home-based community programs, early intervention. It was fascinating. We started moving around the state talking to people about community programs, about what was possible. Don't forget the state schools were growing in leaps and bounds. Community programs were few and far between but people were listening. It was such a struggle but it was a grass roots movement in the best sense of the word. Parents are very powerful in what they can achieve.

Charlotte Aladjem, President
of the Massachusetts
Association for Retarded Citizens

We traveled all over the state working to get local chapters up and running. The state school superintendents had a lot to say. As parents, we had no say at all. The state schools were charging parents. One of the things we did was to get those charges dropped. We went to the State House. We identified thirty bills we would work on, reviewed every bill. Pretty soon they began to pay attention.

Don Guild, President,
founding member of the
Massachusetts Association for Retarded Children

In 1961, President John F. Kennedy appointed a panel of 27 scientists and specialists to prepare A National Plan to Combat Mental Retardation. This became part of the Maternal and Child Health and Mental Retardation Planning Amendments of 1963. \$2.2 million was

allocated to be distributed to states for planning. Lyndon Johnson followed with the War on Poverty and federal dollars became available for social policy. John T. Berry and the Glavin Center were built. Prevention and screening were center stage. Phenylketonuria (PKU), German Measles, and especially poverty, were seen as the most prevalent causes of mental retardation.

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Charlotte Aladjem

In Massachusetts, the mental retardation effort was under the Department of Mental Health. This was the era when they created the area and regional structure that still exists today.

Two planning projects ran from 1964-1966, the Comprehensive Planning Project and the Construction Planning Project. Governor Volpe asked project director Harold Demone to write enabling legislation to implement the findings:

From The Massachusetts Mental Retardation Planning Project, 1966:

Recommendations:

- An Office of Retardation Planning responsible to the Governor should be established to assume the responsibility for developing a coordinated interdepartmental approach to combat mental retardation. The initial operating budget for this office should be approximately \$100,000.
- All future residential facilities should house no more than 500 retarded persons. Plans should be developed to reduce the size of existing institutions to this size.

- A substantial increase in educational services should be provided at the regional centers for the retarded for teaching academic, vocational and social skills to all residents. Particular attention should be given to the severely retarded and chronically ill who are confined to their wards and require "homebound instruction."

Independent of the legislation, the first recommendation of the Mental Retardation Planning Board was to establish a statewide office reporting to the governor to coordinate state action to combat retardation. It was implemented almost immediately.

President John F. Kennedy, Eunice Kennedy Shriver and Arc leaders



As The Arc proceeded through its first full decade, both hope and options were in short supply for people with disabilities and their families.

1962: 8,000 people live in institutions. For residents, these are truly the dark ages. The State Schools are hardly more than human warehouses. Special Education is years away. Group homes are few and far between. Special Olympics has not yet come into being. Few employers hire people with mental retardation. Private placements are limited in availability, and are very expensive and restrictive. Social acceptance is unbearably slow.

1963: Massachusetts becomes the first state to establish testing and treatment for PKU, an inherited metabolic disease that can cause mental retardation if untreated. PKU prevention becomes the national disability model for the U.S.

Arc Massachusetts leaders John Fettinger, Don Guild and Dr. Gunnar Dybwad attend October 23, 1963 White House ceremony, where President John F. Kennedy signs the Maternal and Child Health and Mental Retardation Planning Bill calling for a comprehensive and coordinated plan to address mental retardation (HR 7544).

1966: Governor John Volpe passes Chapter 735, the Massachusetts Mental Health and Retardation Planning Projects, which lays out the current area and regional structure as well as creating a focus on community-based services outside of institutional settings. The concept of using private providers is written into the legislation. The project is administered by Harold W. Demone, Jr., Ph.D., along with William J. Curran, legal counsel and internationally-recognized pioneer in health care law. Arc representatives Don Guild, John Fettinger and Moses Frankel serve on the planning board, along with Burton Blatt and Father Robert Drinan.

1967: An enormously positive event takes place when Dr. Gunnar Dybwad begins his decade of teaching at Brandeis University in Waltham. Formerly a director of the National Association, Gunnar becomes the first director of the Mental Retardation Policy Center at Brandeis' Heller School. From this day forward, Heller becomes a center of learning and advocacy, and Gunnar - along with his wife Rosemary - become generators of knowledge and activity for The Arc.



Ride-a-Bike is launched by the Massachusetts Teachers Association

1969: Ride-a-Bike becomes an important fundraising vehicle, sponsored by the Massachusetts Teachers Association and chaired by Florence Finkel.

Hank DeGrace of New Bedford, John Lopes and Henry Kosior of Fall River spend their vacation walking from Governor Nelson Rockefeller's office in Albany, New York to Governor Francis Sargent's office in Boston to focus community attention on the needs of people with mental retardation.

1960's



VFW members Hank DeGrace, John Lopes and Henry Kosior are congratulated by Gov. Frank Sargent



1967 Board of Directors with president Florence Finkel and Arc poster child



Arc leaders Charlotte Aladjem and Joseph Looney meet with Attorney General Elliot Richardson



Arc leaders meet with Governor Frank Sargent