

The 1950s: The Dawn of Hope

*We came from nothing;
now we stand for something*

FROM THE REPORT OF THE
SPECIAL COMMISSION ON
MENTAL RETARDATION, 1953:



Founders: l-r, Gert Lynch, John Fettinger, Eileen Cunningham, Don Guild and Maury Mezoff, Executive Director

"...although the community was providing for the education and training of the retarded, there was still a relatively large group of mentally retarded persons with emotional and other defects not adequately served. Their community adjustment was difficult and they required at least temporary care in an institutional setting. The Commission noted that the change of the character of the patient population by having a substantial increase of the severely and profoundly retarded under the age of five years in state schools placed new demands on patterns of staffing. In many institutions, the Commission noted ward coverages were at dangerously low levels, and it was not uncommon to find one person on night duty in a dormitory containing over 100 boys and girls."

The Arc began because it was needed. Families were isolated. People with disabilities were hidden away. When parents were told by their doctor that their newborn had Mental Retardation, they were totally devastated and left without hope. Parents were given no other choice but to place their child in an institution. That was the situation facing thousands of families in Massachusetts.

Families began to come together in homes, churches and other settings to support each other. The first local chapters of The Arc (originally the Association for Retarded Children) began to open. Some of the early chapters in Massachusetts included the Greater Boston Chapter (formed in 1945), Franklin County, Hampshire County, and South Norfolk. Without public funding, families developed classrooms and camp opportunities for their children and began clinical nurseries.

1950

The National Arc opens. Massachusetts is one of 14 states represented.

1954

The National Association for Retarded Children holds its second national convention in Boston.

1957

Legislation is passed authorizing the Department of Mental Health to operate fourteen pre-school clinical nurseries.

1959

The 1950's end with the Wagon Train, organized by Rex Trailer, host of WBZ TV's "Boomtown," who worked with The Arc to raise awareness.



Lt. Gov. Robert Murphy greets Rex Trailer at the State House

The Legislature creates a special unpaid commission to investigate training facilities for retarded children.

The Massachusetts Association for Retarded Children is formally recognized.

The Greater Boston Arc opens the first sheltered workshop in the Commonwealth.

1953

1955

1958

Rex leads sixteen vehicles in a wagon train as it journeyed for a week from Greenfield in the Pioneer Valley to the State House in Boston.

The 1960s: Parents Find Their Voice Through The Arc

Government Begins to Take Notice



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

"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 onto Sweden. We started 500 miles north of Stockholm and moved south."

—CHARLOTTE ALADJEM, PRESIDENT OF THE MASSACHUSETTS ASSOCIATION FOR RETARDED CITIZENS

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 was center stage. PKU screening, German Measles, and especially poverty were seen as the most prevalent causes of mental retardation.

RECOMMENDATIONS FROM THE MASSACHUSETTS MENTAL RETARDATION PLANNING PROJECT, 1966:

- 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. 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. Social acceptance is unbearably slow.

Massachusetts becomes the first state to establish testing and treatment for PKU (Phenylketonuria), an inherited metabolic disease that can cause MR if untreated.

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).

1963

1966

Governor John Volpe signs 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.

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 MR Policy Center at Brandeis's Heller School.

Ride A Bike becomes an important fundraising vehicle, sponsored by the Massachusetts Teachers Association and chaired by Florence Finkel.

1967

1969

The 1970s: Humanity Prevails

*The Consent Decree,
Special Education Law Enacted*



Leaders of The Arc prepare for 1978 National Convention.

"...It was frightening period. My life was threatened many times. These communities did not want our children living next to them."

—JANE SMITH, FORMER PRESIDENT, SOUTHERN NORFOLK COUNTY ARC

The seventies was a decade of expanded activism. The darkest emotions of the era reflected the debate over institutional versus community care. At some meetings, Arc members jumped up on tables, threw chairs. Parents who had placed their children in one of the large facilities were passionate that they had made the right decision. The parents who had kept their children at home wanted programs in their own communities.

1970

Chapter 888 is passed, eliminating the financial responsibility of parents if their son or daughter is over 21 and resides within a facility.

1972

First in the nation Federal lawsuit charged that the constitutional rights of the residents of the Belchertown State School were being violated because of the deplorable conditions at this facility. Fernald, Wrentham, Paul A. Dever and Monson were eventually folded into a Consent Decree by which the Commonwealth of Massachusetts settled with the plaintiffs.

1974

Massachusetts Special Education Law (Ch. 766), the first such law in the nation, is enacted. This historic, highly acclaimed legislation, entitles thousands of children to appropriate education. The Federal Law, 94-142 (later called IDEA) would be enacted in 1978.

1975

In response to class-action suits brought against the five State Schools, US District Judge Joseph Tauro issues the historic Consent Decree, which enforces humane standards in the state schools and calls for the movement of thousands of residents to clean and safe community homes. The Arc obtains the "Community Plan," which serves as the foundation for the service system.

1978

Greater Boston Arc, under the leadership of Executive Director Bill Perry and President Frank Donnelly, host the National Convention of The Arc. It is a great success!

The Arc of Massachusetts and Gunnar and Rosemary Dybwad co-sponsor the first Self-Advocacy Conference, called Yes We Can.

The Citizen Advocacy Program, matching individual advocates and people with Mental Retardation, becomes a rich part of The Arc's history. 1100 "matches" are created.

1973

The 80-20 policy becomes more contentious. This policy, enacted by the Department of Mental Health, Division of Mental Retardation, required that 80% of the residents in all new group homes be from one of the five state schools, with the remaining 20% from the community.

The Arc of Massachusetts and the Mental Health Legal Advisory Committee receive a grant to co-host a Center for Law and the Handicapped, which eventually becomes the Disability Law Center.

1977

The Arc of Massachusetts purchases a building at 217 South Street in Waltham that becomes the state office.

1979

The 1980s: Great Strides Forward

Turning 22, Family Support and a new Department of Mental Retardation

"My daughter, Maura, was a student at the Massachusetts Hospital School where she was the Queen of the May, but she was turning 22 and there were no community services out there for her after her birthday. She stayed at home for two years because there was no funding. It was difficult because she has excellent verbal skills but is quadriplegic, so there were few opportunities.

—MAUREEN SULLIVAN, ARC BOARD MEMBER, 1988-1999



Richard and Edith Frye join Bobby Orr at Distinguished Citizens reception.

The Arc filed the first in the nation Turning Twenty-Two legislation, guaranteeing services for students leaving Special Education. The concern was whether we could get through another right to services entitlement similar to Chapter 766. Families who kept their children at home were beginning to get limited supports. The other major development in this decade was the growth of Early Intervention.

1980

Respite Care is launched with a \$500,000 state budget line item.

1981

In a major victory for community services, the Medicaid Home and Community Based Services (HCBS) Waiver is enacted. The Waiver allows the federal government to reimburse state costs for community services as it does for institutional care, removing the state's financial disincentive for community services.

Early intervention for infants, from birth to age three, begins at Minute Man Arc. Children from birth to three with either developmental disabilities or considered at risk receive in-home physical therapy, speech therapy, nutritional supports, etc. Early Intervention now serves over 35,000 children each year.

1987

A new Department of Mental Retardation (DMR) is established after a long battle by Arc advocates. Mary McCarthy is the first Commissioner.

The Arc of Massachusetts secures passage of Chapter 633, a law that allows the Commonwealth to provide transportation to individuals who are competitively employed.

Wrentham and Paul A. Dever Chapters leave The Arc of Massachusetts due to The Arc's support for community services over institutional settings.

1982

Following a concerted campaign by Arc advocates, the landmark Turning 22 (Chapter 688) law was enacted, becoming a national model (though funding was left to the Legislature). Though not an entitlement to services, it was an entitlement to a Transition Plan that assigned individuals to agencies such as the Massachusetts Commission for the Blind or the Bureau of Mental Retardation.

1983

The Arc plays a leadership role in expanding the Personal Care Attendant (PCA) Program for people with cognitive disabilities (regulations are not implemented until 1992). The Disability Law Center, Greater Boston Legal Services, Boston Center for Independent Living and CORD are partners in the effort.

The Arc of Massachusetts works with advocates to establish the Disabled Persons Protection Committee.

1988

The 1990s: Family to Family

Forceful Advocacy Tackles the Waiting Lists

"As Ed approached the age of 40, and we were both approaching 70, we found it harder than ever to care for him all the time – day and night – when he had severe seizures. We all needed a better living situation than Mom and Dad could provide, but there weren't any affordable or adequate alternatives."

—MARY ANN BOULET, MOTHER OF EDMUND BOULET



Arc and Massachusetts Developmental Disabilities Council advocates receive proclamation from Governor Weld.

Families who had chosen to keep their family member at home were getting old and simply afraid to die. Few spaces were available after twenty years of the eighty-twenty rule (eighty per cent from state schools, twenty per cent from the community). Families were afraid that if the parent was no longer able to provide care, the family member would go to a nursing home, a tragedy after a lifetime of living at home.

1990

The Americans with Disabilities Act is passed by Congress and signed into law by President George H.W. Bush.

The Arc of Massachusetts' Executive Director, Philip Campbell, becomes Commissioner of the Department of Mental Retardation, Leo V. Sarkissian becomes the new Executive Director.

1991

New leaders and partners emerge, strengthening the movement, as Massachusetts Families Organizing for Change (MFOFC) is established and Massachusetts Advocates Standing Strong (MASS), the consumer voice for people with cognitive disabilities, grows.

1993

The Consent Decree ends and the Governor's Commission on Mental Retardation is established, making the Department of Mental Retardation Waiting List its number-one priority.

Massachusetts significantly expands the Home and Community-based Waiver, transitioning hundreds of people from community based intermediate care facilities to more flexible home and community supports.

An unprecedented Arc parent conference on Turning 22 fills the Great Hall at the State House. The interim report on the Massachusetts Task Force on Access of Victims and Witnesses with Mental Retardation to the Criminal and Civil Justice Systems is released on May 23, 1993.

1994

Thanks to the efforts of The Arc, a line item for the unserved is finally reinstated in the Department of Mental Retardation state budget. The Arc's Government Affairs Committee assigns top priority to increasing salaries for direct care professionals. John T. Berry Regional Center is closed.

The Arc battles against the use of painful aversive therapy by the Behavioral Research Institute (later renamed the Judge Rotenberg Center). Belchertown State School closes.

1992

Supported by a Joseph P. Kennedy, Jr. Foundation grant, The Arc joins with Mass. Families Organizing for Change and DMR Citizen Advisory Boards to form Family to Family, a collaboration dedicated to addressing the issues of the DMR Waiting List.

1996

Gerald T. Morrissey is named Commissioner of the Department of Mental Retardation.

1997

The Rolland lawsuit, in which The Arc is a representative plaintiff, is settled, moving 1500 people with developmental disabilities from nursing homes to community services. Gunnar Dybwad receives the first DMR award, created in his honor.

1999

The 2000s: Family Supports

*People with Cognitive Disabilities
Speak for Themselves*

"James was three years old when he was admitted to a pediatric facility. We could no longer take care of him. When he was six, Dr. André Blanchet asked us if we could take James home if we were given adequate supports. We jumped at the chance. That was ten years ago."

—MARY ELLEN MAYO CHAIR, THE ARC OF MASSACHUSETTS,
GOVERNMENT AFFAIRS COMMITTEE



Evelyne and Reggie Milorin present at Arc/MDDC legislative reception.

A new century began with a bang as Judge Douglas Woodlock ruled on the Boulet case, that the state must pay for the 2437 individuals on the Waiting List at the Department of Mental Retardation. Between 2000 and 2006, every person must be served. This was a huge turning point for families. A system that had been completely driven by people moving from the large facilities could now focus on the thousands of community families in need. So many parents were in crisis and now would have the opportunity to see their son or daughter move into their own home.

2000

The decade opens with a huge victory for families. The Arc-sponsored Boulet lawsuit – named for Edmund Boulet, son of Arc members Gerald and Mary Ann Boulet – is settled, providing services for 2,444 people on the DMR Waiting List. Neil V. McKittrick, now a partner at Ogletree Deakins, argues the case in U.S. District Court, winning pro bono service awards from both the Massachusetts and American Bar Associations.

Evelyne and Henry Milorin spearhead The Arc's effort to reach out to diverse cultural groups. Evelyne would later become a Kennedy Fellow and winner of the Barbara Gopen Award.

2001

In partnership with the Department of Mental Retardation and Shriver Clinical Services, Family to Family coordinated fifteen Support Centers, providing clinical supports, bi-weekly support groups and mentoring to Boulet families. Dan Becker, Maureen Sullivan, John Nadworny, Cindy Haddad, and others provide leadership. Jim Brett succeeds Marty Krauss as Chair of the Governor's Commission on Mental Retardation. Jim becomes the Chair of the President's Commission for People with Intellectual Disabilities. The DMR budget is reduced by \$44 million. The Arc joins with partners to lead a rally in front of the State House that stops traffic and business on Beacon Street. Thousands within The Arc community participate over several months of advocacy. Their combined efforts pay off: the funds are almost completely restored.

2005

The Arc of Massachusetts hosts Advocates for Autism of Massachusetts (AFAM).

The Arc, under the leadership of President André Blanchet, M.D., implements capacity building and innovation projects through the support of the Ronald W. Findlay Trust, which gives The Arc a grant of nearly \$1 million to provide transition support to families.

The Paul A. Dever State School is closed.

2002

Massachusetts Families Organizing for Change celebrates the passage of Chapter 171, An Act to Support Individuals and Families with Disabilities. Governor Mitt Romney calls for the closure of the Fernald State School.

2003

With a record crowd rally in front of the State House, The Arc leads the fight to restore funding in the FY05 budget for work, day, and transportation services for 800 people. The Arc-sponsored Workforce Study Bill is passed. The bill is a key step in raising wages for direct care workers. The Arc makes good use of its online Action Center, which allows constituents to contact their legislators electronically on issues of importance to The Arc. The Arc of Massachusetts and its constituents outperform all other Arc chapters in the nation in e-mail output. Massachusetts online advocacy matches the output of all other states combined. Mass. Advocates Standing Strong files legislation to eliminate use of the pejorative word "mental retardation" by changing the name of the Department of Mental Retardation (DMR) to the Department of Developmental Services.

2004



The Arc 2004 Board of Directors.



James Mayo goes to the prom.

2006

The Arc advocates to restore more flexibility in eligibility regulations to reflect functional needs as DMR implements stringent limits based on IQ. Legislators Karen Spilka, Kay Khan, Barbara L'Italien, Tom Sannicandro and others help.

The Arc advocates with legislators for a new allocation for families who have children with autism as part of the Family Support line item. Conference Committee funds Autism Children's line item at \$1.2 Million.

2008

In November, The Arc releases its health care access report, *"Left Out in the Cold,"* with primary support from the Boston Foundation. Authors Ruth Freedman (Boston University School of Social Work), Mandy Nichols and Rolanda Ward outline barriers to quality health care. We publicly present the findings three months later and the *Boston Globe* exclusive runs on the front page of Metro Section, "Seeking Grown up Care."

On December 12, Governor Deval Patrick announces closure of four institutions- Fernald, Glavin, Monson and Templeton-to be completed in 2013.

The Collaborative (a combination of three trade organizations) leads efforts in the passage of Chapter 257, which will reform how the Commonwealth pays agencies for provision of essential social services. The Arc supports passage.

On December 6, The Arc kicks off SUPPORTbrokers led by Evelyn Hausslein to provide independent, fee-based consultation to families and individuals on person-centered planning, problem-solving and obtaining supports or services. The project is intended to mirror, on a personal level, The Arc's systems advocacy with all branches of government. The reception includes EOHHS Assistant Secretary Jean McGuire and Michael Smull, a national speaker on person-centered planning.

Cuts of \$80 Million are prevented. The Arc and ADDP host a State House rally with over 1,000 people. Folk music icons and social activists Peter Yarrow and Noel Paul Stookey of Peter, Paul and Mary perform at the rally.

2007

2009

The 2010s: Access and Choice

*Opening doors to DD and MassHealth;
Self-determination through Real Lives*

"QUOTE GOES HERE"



//

- NAME

2010

August 3, ARICA is signed into law, requiring insurance companies to pay for diagnosis and treatment of autism spectrum disorder.

The Arc of Massachusetts receives one of five major Walmart Transition grants from The Arc US.

Pat Pakos leads the effort with Kerry Mahoney at The Arc of Greater Haverhill/Newburyport.

2012

Legislation to expand choice and self-direction for individuals and families is filed by Tom Sannicandro for a second session, now named "Real Lives."

The Friendships Project begins in collaboration with DDS. Goal is to advance relationships between individuals with and without disabilities. Training, outreach, and consultation are supported by an active advisory board.

Operation House Call expands from BU School of Medicine to Tufts University School of Medicine and Simmons School of Nursing and Health Sciences.

2013

Medicaid Managed Care for Medicare/Medicaid recipients is introduced which would place control over long term supports at insurance companies chosen by Medicaid. The Arc takes a strong advocacy position to maintain robust services.

Former Representative and future Senator Barbara L'Italien joins The Arc as Government Affairs Director and a stronger partnership with AFAM is forged as we look to pass legislation reflecting recommendations from the Governor's Commission on Autism.

HealthMeet is launched at The Arc as Massachusetts is one of six states partnering nationally in conjunction with our national affiliate and the CDC. (Centers for Disease Control)

Demographics continue to evolve as chapters report that over 50% of the individuals they serve through family support have family members with an autism spectrum disorder.

2014

The Arc plays a key role in passage of four important pieces of legislation in the 2013-2014 session—Real Lives, Autism Omnibus bill, National Background Check and the addition of a data study of autism in the IT Bond bill.

Efforts to renew support for The Arc increase as Vice President Tracy Atkinson of State Street leads the most successful fundraising event since our 50th Anniversary. During the fall Gala, a lead capital gift to establish the Daniel, Angela and Michael Becker Center for Advocacy is announced.

A new department for Education and Outreach is initiated at The Arc, with Kerry Mahoney as director. Webinar programs and a family support network are expanded

On November 13, the Fernald School finally closes its doors.

The Arc with other groups successfully prevents cuts in three Medicaid services – Day habilitation, Adult foster/family care and Adult day health. Operation House Call arrives at The Arc; Susanna Peyton oversees the transition. OHC trains medical students and other graduate level health professionals (nurses, therapists, etc.) in essential skills to enhance the health care of persons with intellectual/developmental disability. All Aboard The Arc kicks off its first year in Worcester with Dan Sullivan, Dan Rea, Steve Nelson and others as headline speakers. The Arc begins planning for a new building and a Capital Campaign.

2011

The Arc works with DDS, EOHHS, Medicaid, MEFA and others on implementation of the Autism Omnibus bill and the Real Lives Bill.

Architectural plans for new office building at its present site are completed. The Arc reaches two-thirds of its goal for the Capital Campaign and groundbreaking is scheduled. Affiliates agree to significantly increase their commitment for statewide advocacy and education. The Arc identifies a staff registry for abuse and neglect as one of its highest priorities.

2015