The 50’s: The Dawn of Hope

We came from nothing; now we stand for something

Our son, Donald, was placed at the Paul A. Dever School when he was only six-years-old. He cried twenty-four hours a day. We couldn’t sleep. I was afraid my husband, Harry would get killed on the road. We had no place to turn, nobody to help us. We could only see him every other Sunday from 10:00 till 12:00 in the morning. Imagine being told you could only see your six-year-old twice a month. It was terrible.

Some of the local chapters were running nursery schools, but there was no funding. Everything we did was a battle. Greater Boston had begun in the forties but Arcs were happening around the state. The first time we met to form a state association was some place in Framingham. Nobody had any money. It was a struggle from day one.

The big issue was the Community Clinical Nursery Schools. We wanted the state to take them over. The state refused. Fine. I told them, we’ll take all the kids to the State House. “You wouldn’t,” said Lew Klebanoff, who was head of the Bureau of Retardation. “Watch me,” I said. Eventually the state took them over. “Provide vs. obtain” was a big issue. We knew we couldn’t run these programs forever.

One day a young man died at the Fernald School. His mother, who had died before him, had been a friend of mine from GBARC. I felt I should go to the funeral. I called Fernald and couldn’t find out anything, so I called the rabbi who was affiliated with the facility to ask where the funeral was taking place. “Funeral,” he said and sort of laughed. “There’s no funeral. We sold the body to Harvard for $50.00.” There was no money to bury people. When I was president, the big thing was to create a fund for indigent people.

Florence Finkel, a founding member of the Massachusetts Association for Retarded Children, 1955

From the report of the Special Commission on Mental Retardation, 1953:

“… 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.

1953: The Legislature creates a special unpaid commission to investigate training facilities for retarded children.

1954: The National Association for Retarded Children holds its second national convention in Boston.

1955: The Massachusetts Association for Retarded Children is formally recognized.

1957: Legislation is passed authorizing the Department of Mental Health to operate fourteen pre-school clinical nurseries.

1958: The Greater Boston Arc opens the first sheltered workshop in the Commonwealth.

1959: The 50’s end with the Wagon Train, organized by Rex Trailer, host of WBZ-TV’s “Boomtown,” who worked with The Arc to raise awareness. Rex led 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 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 Dybdal 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.

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.
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.

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.
The 70’s: Humanity Prevails
The Consent Decree, Special Education Law Enacted

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.

In 1972, the first-in-the-country 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. A new chapter in the Arc’s colorful history unfolded. The Arc of Massachusetts was Co-Plaintiff with the parent groups at the Paul A. Dever and the Wrentham State Schools. Under the guidance of the law firm of Hill and Barlow, first with Bo Jones and then Nonnie Burns, parents leaders soon learned the best routes to the McCormack Federal Court House to sit in Judge Joseph Tauro’s courtroom. The Fernald, Monson and Belchertown parents groups were represented by the indomitable Beryl Cohen, Charlotte Aladjem, Florence Finkel, Attorney Paul Jameson, President Joseph Buonomo and Gunnar Dybwad represented The Arc.

The movement from the facilities launched the saga of the purchase of services (POS) system. Francis Sargent, Republican governor from 1969 to 1974, made the decision to release public dollars to private vendors. Peter Goldmark, Secretary of the Executive Office of Human Services, allocated money to open a series of group homes. Initially, the primary providers were local Arcs hoping to include people from the community in their programs. Eventually, Vinfen, Bay Cove, DARE, Justice Resource Institute, and hundreds of other non-profits joined them as service providers. Throughout the years, The Arc of Massachusetts continued to be the locomotive pulling the train, with legislative initiatives, lawsuits and budget advocacy campaigns inching the system along.

The Arc of Massachusetts argued for a Community Plan to protect the former residents of the facilities who were moving by the thousands into community settings. Gail Grossman, The Arc’s Director of Governmental Affairs, drafted the plan with Assistant Commissioner of Mental Retardation, Linda Glenn.

In 1975, Governor Michael Dukakis signed the Consent Decree on the five state schools. Visiting these facilities, Governor Dukakis, along with busloads of legislators, saw the squalid conditions people were living in. However, as a Democrat, he also had a commitment to public employees who depended on the jobs at the large facilities. The provider vs. organized labor debate continues as a major issue today.

As people moved out of hiding into community settings, battles were brewing everywhere. People worried about the value of their property going down if a group home opened up next to them. Hundreds of ordinary citizens appeared at town meetings to voice opposition to community residences. The Arc supported the Fair Housing Act, designed to prohibit discrimination against persons with disabilities. Local Arcs were on the firing line.

At the same time that Massachusetts was arguing about where people should live, the Commonwealth passed another first: Chapter 766, The Right to Education Act, allowing every child, regardless of the extent of one’s disability, to attend public school. For many, the thought that their child could go to school with his brothers and sisters was mind-boggling. Working closely with Speaker David Bartley and Education Chairman Michael Daly, Arc leaders played a major role in the passage of this landmark legislation. On the federal level, PL 94-142, passed in 1978 and based on Massachusetts law, allowed children throughout the nation to begin to attend public schools.

New clichés became commonplace:
Provide versus Obtain
Eighty – Twenty
Deinstitutionalization
Class versus non-class
Normalization

It was a 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
1970: Chapter 888 is passed, eliminating the financial responsibility of parents if their son or daughter is over 21 and resides within a facility. Congratulations are given to Joseph Walsh, Chairman of The Arc of Massachusetts' Governmental Affairs Committee, and board member Don Guild.


1973: 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.

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.

1977: 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.

Community Clinical Nursery Schools are transferred from the Department of Mental Health to the Local Education Authorities.

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.

1979: The Arc of Massachusetts purchases a building at 217 South Street in Waltham, which becomes the state office.
The 80’s: 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

Wearing Don’t Turn Twenty-Two badges, The Arc filed the first in the nation Turning Twenty Two legislation, guaranteeing services for students leaving Special Education. The parents were coming out of the woodwork, showing up at the State House, at The Arc’s 217 South Street office, at our local chapters. The concern was whether we could get through another right to services entitlement similar to Chapter 766. In 1983, with assistance from the Disability Law Center and Human Service Co-Chairs, Senator Jack Backman and Representative Joseph DeNucci, Chapter 688 was passed. 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. It forced the agencies to identify the number of students entering the community services system each year and let advocates know which agencies people were transitioning to.

Hardened reporters, along with anxious parents, packed State House press conferences. Everyone was crying. It wasn’t perfect, but eventually funding was attached to the law and people stopped showing up at the State House. We knew we were making progress.

Families who kept their children at home were beginning to get limited supports. Weekend Respite Care was started in 1981, but the Commonwealth wanted a sliding fee scale. With Lucie Chansky leading the way, $500,000 was allocated with no sliding fee. This program, known as flexible supports, is now funded at more than $50,000,000 - serving over 12,000 families.

As the consent decree continued to move hundreds of people into community-based settings, the bureaucracy was still encumbered by a medical model of service delivery. Advocates could see a day when no institutions were necessary. Individuals with disabilities were thriving in community-based settings, reaching plateaus no one ever imagined. At the same time, employers began to find people with disabilities to be top-notch employees, and sheltered workshops started the shift to supported employment. Dr. William Kiernan, The Arc’s Vice President, became the leader for employment services.

Direct care salaries demanded center stage. The quality of care became the single most important issue.

In 1987, legislation filed by The Arc was passed which split the Department of Mental Health into two entities: a Department of Mental Health and a new Department of Mental Retardation. There was no overlap; there were separate Citizen Advisory Boards and separate area and regional offices. Mary McCarthy was named the first Commissioner of the Department of Mental Retardation.

The other major development in this decade was the growth of Early Intervention. Started at the Minute Man Arc in 1981, children from birth to three with either developmental disabilities or considered at-risk were receiving in-home physical therapy, speech therapy, nutritional supports, etc. Early Intervention now serves over 35,000 children each year.

The state budget took a downturn toward the end of the decade, putting extreme pressures on Department of Mental Retardation services. Public hearing rooms at the State House drew standing-room-only crowds of parents and advocates from The Arc.
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... Joseph Buonomo becomes President of the National Arc.

1982: Wrentham and Paul A. Dever State School Chapters leave The Arc of Massachusetts due to The Arc's support for community services over institutional settings.

1983: Following a concerted campaign by Arc advocates, the landmark Turning 22 (Ch. 688) law is enacted, becoming a national model (though funding was left to the Legislature).

1985: The Turning 22 Coalition of parents is formed under the tireless efforts of Lee Vorderer, working with many Arc members: Dan Becker, Jim Kerkam, Jerry McCarthy, Maureen Sullivan, and Eileen Sousa. Mary Ann Walsh, now at The Arc of the South Shore, becomes head of the Bureau of Transitional Planning at the Executive Office of Health & Human Services.

1986: Phil Gloudemans recruits Boston Bruins' legend Bobby Orr to become a spokesperson for The Arc of Massachusetts.

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.

1988: 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.

Phil Gloudemans, Steve Nazro of the Boston Garden, Colleen Turner and Executive Director Philip Campbell launch Play on the Parquet, an annual fundraiser, now held at the TD Banknorth Garden.
The 90’s: 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

As thousands of people moved from Fernald, Monson, Wrentham, Paul A. Dever and Belchertown, the community system was growing rapidly, but the salaries of direct care workers continued to be a major issue. Ongoing budget efforts throughout the decade, including the Campaign for Access and Excellence and Do the Right Thing, translated into funding for front line staff. The Association for Developmental Disabilities Providers (ADDP) is a strong partner in these efforts.

However, 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 percent from state schools, twenty percent 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.

As it became more common to have a group home in your neighborhood, the role of institutions was beginning to end. The Belchertown State School was closed in 1992 and The Arc’s leaders foresaw the day when there would be no more facilities. Former Arc Executive Director Philip Campbell was now the Commissioner at the Department of Mental Retardation. He joined Governor William Weld and Judge Joseph Tauro in signing the motion to end the state school consent decrees. The Governor’s Commission on Mental Retardation was formed to oversee the transition.

One of its first initiatives was to hold a series of oversight hearings on the Waiting List at the Department of Mental Retardation. Hundreds of families showed up at the Great Hall in the State House to tell their stories.

In 1996, through the leadership of Dr. Marty Krauss, funding was obtained from the Joseph P. Kennedy, Jr. Foundation to support the establishment of Family to Family to address this Waiting List. With The Arc of Massachusetts as the host, along with Massachusetts Families Organizing for Change and the Citizen Advisory Boards of the Department of Mental Retardation, Family to Family was launched.

Arc member Dan Becker chaired the Steering Committee and Dr. Allen Crocker chaired the Advisory Board. Brandeis student Diane Griffiths surveyed 250 parents to identify needs and hear what families were looking for. Only four said they would consider an institutional setting. Following passionate testimony at the State House before the House and Senate Ways and Means committee by Steering Committee members Art Shelley, Evelyne Milorin, George Smith and Larry Pahigian, $5.9 million was allocated for the Waiting List in 1998 and $10 million in 1999.

However, a history of neglect indicated that there were still more than 3,000 families waiting for services. In 1999, with the leadership of The Arc, eight parents filed a Class Action suit in federal court on behalf of these waiting list families. Neil V. McKittrick of Hill and Barlow agreed to take on the case on a pro bono basis and Edmund Boulet became the lead plaintiff in what would become known as the Boulet lawsuit.

One year before, the Rolland lawsuit was filed, addressing people with disabilities living in nursing homes. 1,500 people would move from nursing homes into community settings as a result of this action.
1990: The Americans with Disabilities Act is passed by Congress and signed into law. The Arc of Massachusetts Executive Director, Philip Campbell becomes Commissioner of the Department of Mental Retardation. Leo V. Sarkissian becomes new Executive Director.


Theresa Varnet, future president of The Arc, inaugurates a series of training sessions on Future Care Planning.

The Arc battles against the use of painful aversive therapy by the Behavioral Research Institute later renamed the Judge Rotenberg Center.

1993: The Consent Decree on the five state schools ends and the Governor's Commission on Mental Retardation is established. Led by Chairperson Marty Krauss, Ph.D and Staff Director Mary Ann Allard, the Commission takes on the DMR Waiting List as its number one priority.

Massachusetts significantly expands the Home- and Community-based Waiver, transitioning hundreds of people into flexible home and community supports.

An unprecedented Arc parent conference on Turning 22 fills the Great Hall at the State House.

The interim report of the Massachusetts Task Force on Access of Victims and Witnesses with Mental Retardation is released. Joe and Doris Buonomo, Alex Moschella, Rep. Carol Donovan and others along with District Attorney Thomas Reilly, advance recommendations to ensure that individuals with cognitive disabilities are able to testify in court.

1994: The John T. Berry Center is closed.

The Governmental Affairs committee assigns top priority to increasing salaries to direct care professionals. Concerns about safety drive the debate. Sheri McCann and Gerry McCarthy are among the most effective advocates.

1995: Leaders and founders is organized as The Arc’s major fundraising effort. Don Stewart, Joe Andrade, Joe Amhass, Hal Demone, Don Freedman, Bill Kiernan, Ray Nickerson, Jane Smith and Maureen Sullivan play key roles.

1996: Supported by a Joseph P. Kennedy, Jr. Foundation grant, The Arc joins with Massachusetts Families Organizing for Change and the DMR Citizen Advisory Boards to form Family to Family, a program dedicated to addressing the waiting List at the Department of Mental Retardation. Allen Crocker, MD and Marty Krauss are named Co-Chairs. Dan Becker is Chair of the Steering Committee.

1997: Gerald T. Morrissey is named Commissioner of the Department of Mental Retardation.


1999: The Rolland lawsuit, in which The Arc is a representative plaintiff, is settled moving 1500 people from nursing homes to community services and obtaining specialized services for hundreds more… Gunnar Dybwad receives the first DMR award. Arc members Florence Finkel, Allen Crocker, Dan Becker, Mary Lou Maloney, Emily Nisenbaum and Jim Brett would receive subsequent awards.
The 2000’s: 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,
Governmental Affairs Committee

A new century began with a bang, as Judge Douglas Woodlock ruled on the Boulet case, that the state must pay for the 2,437 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.

With support from the Department of Mental Retardation and Shriver Clinical Services, Family to Family received a grant to coordinate fifteen Support Centers, providing clinical supports, bi-weekly support groups and mentoring to Boulet families.

In 2002, the Paul A. Dever School closed and Governor Mitt Romney called for the closing of the Fernald School. Some parents reacted with the same passion as they had thirty years ago in opposition to the decision. The facility remains open.

This excitement and progress did not last too long, as the economy soured and services were being cut. Dental care, prescription glasses, and prosthetic devices were taken away, and in 2004 Governor Romney announced that 800 people would lose day and work opportunities. This did not sit well with The Arc of Massachusetts, and in no time we were blocking Beacon Street with the hundreds of individuals and families protesting these proposed cuts. Full funding was restored.

With the internet, The Arc is able to connect with thousands of families instantly. Universal Health Insurance is on the front burner. The Self-Advocates do not want to be called Mentally Retarded. Through Massachusetts Advocates Standing Strong, legislation was filed to change the name of the Department of Mental Retardation to a Department of Developmental Services.

The Findlay Trust provided a tremendous boost by giving The Arc of Massachusetts a grant of nearly $1 million for capacity building and innovative projects.
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 2,437 people on the DMR Waiting List. Neil V. McKittrick, now a partner at Goulston & Storrs, argues the case in U.S. District Court, winning pro bono service awards from both the Massachusetts and American Bar Associations.

Evelyn and Henry Milorin spearhead the Arc’s effort to reach out to diverse cultural groups. (Evelyn would later become a Kennedy Fellow and winner of the Barbara Gopen Award.)

2001: The entire disability community mourns the death of Gunnar Dybwad.

Jim Brett succeeds Marty Krauss as Chair of the Governor’s Commission on Mental Retardation.

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.


2003: Massachusetts Families Organizing for Change celebrates the passage of Ch.171, an Act to Support Individuals and Families with Disabilities.

New England Patriots owner Bob Kraft visits the State House to see his son Joshua receive an award for helping kids with disabilities. Ann Jones, Sherri Dottin, Maureen Sullivan, and Lucie Chansky continue their good work in organizing the Distinguished Citizen Awards.

Governor Mitt Romney calls for the closure of the Fernald State School.

2004: 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. Under the leadership of Action Center administrator John Thomas, 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.

GBArc, supported by The Arc in Massachusetts and spearheaded by CEO Terri Angelone and President Dick Beard, hosts the 2004 National Convention of The Arc of the United States. The consensus feedback is that the convention is “a fabulous event.”

Governmental Affairs Committee parents are recognized for their good work: Carol Beard, Julia Blake, Lucie Chansky, Evelyn Hausslein, Mary Ellen Mayo, Jerry Silbert, George Smith.

Mass. Advocates Standing Strong files legislation to eliminate use of the pejorative term “mental retardation” by changing the name of the Department of Mental Retardation (DMR) to the Department of Developmental Services.


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.

Fifty years is a lifetime ... but our work is never done.
The Lawsuits

In fifty years, The Arc of Massachusetts has accomplished more than most organizations could dream about. We could not have done as much without the efforts of lawyers, judges and scholars who affirmed the legal rights of individuals with disabilities, primarily through federal court. The results of these landmark cases have created a new world for people with disabilities.

1972 Ricci vs. Greenblatt
Following the death of four people at the Belchertown State School, parent Ben Ricci - in cooperation with The Arc of Massachusetts - filed the first lawsuit in federal court challenging that the constitutional rights of the residents at Belchertown were being violated. Charlotte Aladjem, Gunnar Dybwad, and Beryl Cohen - who became the lead attorney in the case - filed the papers in federal court. This case was expanded to include the Monson Developmental Center and the Fernald State School. Joseph Tauro was the presiding judge in this and the other consent decree cases, which were eventually consolidated under one decree.

1973 The Arc of Massachusetts vs. Dukakis
Along with local Arc parent groups from the Wrentham and Paul A. Dever State Schools, The Arc of Massachusetts filed this case in federal court, challenging that the constitutional rights of residents in these facilities had been violated. Hill and Barlow agreed to represent the class on a pro bono basis. Attorneys Bo Jones and Nonnie Burns were the attorneys of record, and partners Richard Renehan and John Vincent invested thousands of hours representing the men and women at these facilities.

1975 Consent Decree
A Consent Decree is signed by Governor Michael Dukakis agreeing to bring these five facilities - Belchertown, Dever, Fernald, Monson, and Wrentham - up to Federal Title 19 Medicaid status.

1976 Brewster vs. Dukakis
At the request of the Center for Public Representation (CPR), The Arc of Massachusetts filed an amicus brief on behalf of the individuals with mental retardation living at Northampton State Hospital. Hill and Barlow attorneys Richard Renehan and John Vincent prepared the amicus brief for The Arc. The case resulted in a consent decree which mandated the creation of a comprehensive system of less restrictive alternatives for all residents of the Northampton State Hospital, resulting in the closure of the institution.

1977 Superintendent of Belchertown State School vs. Joseph Saikewicz
This was the first Massachusetts case, and the second major case in the nation, to discuss whether a legally incompetent person has a right to die. Joseph Saikewicz, a man with profound mental retardation living at Belchertown, was diagnosed with a fatal type of leukemia and given a 50% chance of temporary remission with chemotherapy. A court-appointed guardian recommended that treatment not be administered; a probate judge concurred, and an appellate court upheld this decision. The court decided that incompetent patients should not be denied a right to refuse treatment, and established the standard of substituted judgment - the right of a court to determine what decision the patient would have made, if competent.

1995 Mahoney vs. Weld (Healey vs. Weld)
This case began in 1994 to address legislative language which prevented individuals from leaving state institutions to move into the community. This language placed the continued existence of the institutions and staff positions above the residents’ civil rights. The Center for Public Representation played a key role in this case. Attorneys Michael Boudett and David Geiger of Foley, Hoag & Eliot and Frank Laski filed the case. Massachusetts Superior Court ruled that the state statute prohibiting discharges from certain institutions (which were targeted for closure) was unconstitutional.

1998 Olmstead vs. L.C. and E. W. (United States Supreme Court)
At risk in this landmark case were the substantial gains of the Americans with Disabilities Act (ADA). In 1998, during his work on the Boulet case (see below), Neil V. McKittrick was asked to represent 58 former state commissioners who were supporting the rights of individuals with disabilities in this case through an amicus brief. Ms. Deborah Hesford Dos Santoss assisted Neil as counsel. Ultimately, the Supreme Court ruled in favor of community settings over institutions, stating that unnecessary institutionalization constitutes discrimination and segregation, and violates the ADA’s integration mandate, which requires community placement of people with disabilities.

1999 Rolland vs. Cellucci
The Arc of Massachusetts was one of two organizational plaintiffs in this case, which was filed by Steven Schwartz and Cathy E. Constanza of CPR; Christine M. Griffin, Stacie B. Siebrecht, and Matthew Engel, Disability Law Center; Frank Laski of Mental Health Legal Advisers Committee; and Richard Belin of Foley, Hoag & Eliot. The case argued that individuals with developmental disabilities who resided in nursing homes had a right to community services, and to specialized services within nursing homes. 1,600 individuals were positively affected by the settlement in this case, with 750 people slated to move into community settings over seven years.

2000 Boulet vs. Cellucci
This case was filed on behalf of eight individual plaintiffs, who had been waiting for services from the Department of Mental Retardation (DMR) for up to 20 years. Lead counsel Neil V. McKittrick argued the case in U.S. District Court, assisted by Carol V. Rose and David S. Friedman of Hill & Barlow. Prior to the settlement, Judge Douglas Woodlock released an order affirming certain rights to Medicaid-funded services. The Boulet settlement provided $114 million to serve 2,445 people on the DMR waiting list over a five-year period.