



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.

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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, Evelynne 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's

(l) Jerry Kelley
(center) Arthur Shelley
presents testimony on
the Waiting List
(r) Sherri Dottin receives
Distinguished Citizen award



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.

1992: Belchertown State School closes.

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 Ambash, 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.

1998: John Nadworny participates in the Iron-Man Triathlon at Lake Placid, New York to raise funds for Family to Family.

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.



Channel 4's Charles Austin, parent and Advocate, receives award from Arc Presidents Virginia Tisei and Carolyn Barrett



Play on the Parquet with Leo Sarkissian and Ed Markey



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



Family to Family Leaders join John Nadworny at the Iron Man in Lake Placid