

HONORING EUNICE KENNEDY SHRIVER'S LEGACY IN INTELLECTUAL DISABILITY

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We begin in 1958, a significant year in Eunice Shriver's public life and in intellectual disability history as well. According to the medical historian Edward Shorter, in that year Joseph P. Kennedy asked his daughter Eunice and her husband Sargent Shriver to take responsibility for the Kennedy Foundation's new program in the prevention of intellectual disability.

Imagine Joseph P. Kennedy's pride were he to learn that 50 years after giving this assignment to his daughter, the National Institutes of Health's National Institute on Child Health and Human Development, the leading intellectual and developmental disabilities research enterprise in the United States and perhaps the world, would be named in her honor.

However, in 1958, what Eunice Shriver encountered in Washington in intellectual disability (then termed "mental retardation") was challenging to say the least. The environment was characterized by disinterested bureaucracies in the executive agencies, the judiciary and, with the most notable exceptions of Representative John Fogarty and Senator Lister Hill, in the U.S. Congress.

The late Elizabeth Boggs co-founded the National Association for Retarded Children in 1950 and in 1958 was elected its first female president.

"In the mid 1950's," she wrote, "the National Institute on Mental Health privately doubted if as much as \$250,000 could be well spent on a subject as unglamorous as mental retardation."

The federal presence in intellectual disability was so modest that a grant from the Kennedy Foundation for \$1.25 million in 1952 to establish a private school in Illinois exceeded the entire federal budget for intellectual disability services at that time.

In 1958, over 190,000 people with intellectual disabilities, many of them children, were segregated in poorly funded, state-operated residential “schools” and in state psychiatric institutions across the country. To say that these facilities were spartan would be too kind. Mrs. Shriver was quoted in a 1964 *Parade Magazine* article after touring such institutions:

“I have seen sights that will haunt me all my life. If I had not seen them myself, I would never have believed that such conditions could exist in modern America.”

The “sights she saw” were even more vividly summarized in a moving passage she had written two years earlier for *The Saturday Evening Post*.

“I remember well one institution we visited several years ago. There was an overpowering smell of urine from clothes and from the floors. I remember the retarded patients with nothing to do standing, staring, and grotesque-like misshaped statues. I recall other institutions where several thousand adults and children were housed in bleak, overcrowded wards of 100 or more, living out their lives on a dead-end street, unloved, unwanted, some of them strapped in chairs like criminals.”

Eunice Shriver’s most catalytic and lasting contribution to the community integration and institutional reform movement was her leadership in 1961 championing the creation of the President’s Panel on Mental Retardation and in subsequently playing, according to Boggs, “an active role pressing for ever-increasing vigor in the panel’s performance.” Shriver had insisted that only the finest scientists, clinicians and educators be appointed to the panel.

Panel members included Boggs and also Dr. Robert Cooke, Pediatrics Chair at Johns Hopkins University School of Medicine and Kennedy Foundation medical adviser. Cooke led the call for the creation of an NIH “kiddie institute,” which became the NICHD in 1962. Cooke, who led the biomedical task force, and Boggs, were both parents of children with intellectual disabilities. The brilliant parent-advocate Boggs held a Ph.D. in mathematical chemistry from Cambridge University, and lead the panel’s Task Force on Coordination. She was also vice chair of the Task Force on Law. Boggs later wrote that:

“The idea of the panel was urged on the president by his sister Eunice Shriver.”

The panel would have only 11 months to complete its work in time to accommodate the Congressional calendar so that recommended legislation might be introduced, enacted and funded. It organized itself into six task forces: Prevention, Education and Habilitation, Law and Public Awareness, Biological Research, Behavioral and Social Research, and Coordination.

The panel held public hearings in seven major cities, sought technical assistance from a variety of governmental and nongovernmental sources, and also traveled to review facilities in Sweden, Denmark, Holland, England, and the Soviet Union.

The panel’s final report was officially transmitted to President Kennedy on October 16, 1962 at a White House event held during the top secret build-up of the 1962 Cuban missile crisis. The president made no mention of it while meeting with the panel.

The overarching theme in the panel’s final report was that future services for people with intellectual disabilities should be provided “as close as possible” in community and family settings as opposed to large and remote state operated residential institutions. The panel issued 97 recommendations emanating from its six task forces.

Two groundbreaking statutes were enacted just a few weeks prior to the president’s death in 1963. Public Law 88-156 authorized the nation’s first state planning grant program in intellectual disability, doubled the authorization level for the existing federal maternal and child health state grant program and authorized special grants for maternity and infant care. Public Law 88-164 authorized three interrelated construction programs: Mental Retardation Research Centers (there are 21 today); University Centers of Excellence in Developmental Disabilities (67 today); and 362 projects for community facilities construction.

Thus, in 1963, the federal government initiated the expectation of the reform of intellectual disability services across the states for the first time in the nation’s history. The president’s panel was an unprecedented catalyst for change, and the principal change agent associated with the panel was Eunice

Kennedy Shriver. Three years later, in 1966, she would be honored with the prestigious Albert Lasker Public Service Award in Health.

She would receive many awards in her career, including honorary degrees from Yale, Harvard, Princeton, and Georgetown; the Presidential Medal of Freedom from President Reagan; the French Medal of Freedom and the NCAA Theodore Roosevelt Award. In 2008 she received the inaugural Sportsman of the Year Legacy Award from *Sports Illustrated* magazine.

But Eunice Kennedy Shriver never rested on laurels.

On July 20th, 1968, two years after she received the Lasker Award for work with the Kennedy Foundation and the president's panel, 900 Special Olympians from 25 states and Canada gathered at Soldier Field in Chicago. By that time, Mrs. Shriver had consulted for several years with key leaders in the emerging field of adapted sports for people with intellectual disabilities.

In Chicago, at the first national games, she would announce a "Special Olympics training program for all mentally retarded children everywhere."

Four decades later, more than 3.1 million athletes and over one million volunteers and coaches from 175 countries would be participating. In many of the world's poorest countries, Special Olympics is the principal development program for people with intellectual disabilities. In the past 13 years, with Timothy Shriver's CEO executive leadership and Mrs. Shriver's continuing inspiration and guidance as the founder, the Special Olympics emerged as the leading sports, health promotion, and international development program for people with intellectual disabilities in the world.

Mrs. Shriver faced formidable odds in setting the stage for these outcomes to be achieved. Chief among them were the widely held prejudices in the 1960's that people with intellectual disabilities would suffer physical and psychological harm if they attempted to exercise vigorously, regularly and competitively; that they could not master team sports; and that they were best served in more sedentary camping and recreational activities like eating hot dogs, singing songs and sleeping in tents.

Overly protective “recreationist” assumptions against carefully planned and monitored athletic training and competitions collapsed as tens of thousands of Special Olympics athletes soon proved skeptics wrong by competing in athletic games throughout the country, then throughout the world.

Eunice Kennedy Shriver’s personal qualities were important in her success at the Kennedy Foundation, at the president’s panel, and with the Special Olympics.

Paraphrasing her son Tim, these qualities included a chemistry of political acumen nationally and internationally coupled with celebrity pizzazz; and a deep respect for the role of scientific research on the one hand--delicately balanced with an even deeper appreciation of the inner beauty, courage and potential competence of people with intellectual disabilities on the other. Her qualities of mind and spirit were only strengthened by her dedication to her faith, to her family, to the joy of sport, and to citizen activism.

How do we properly honor her?

Mrs. Shriver would remind us that the greatest challenge in intellectual disability of this generation, and likely of the next, is recognizing and acting on the fact that the vast majority of people with intellectual disabilities in the world today are the scores of millions of people who live day-to-day in developing countries where they are denied health care, education, employment opportunity, basic human rights, personal support and access to emerging technologies.

In many of these countries, Special Olympics organizations are the most viable and often the only nationwide organizations explicitly dedicated to improving the lives of people with intellectual disabilities.

There is no stronger source of inspiration available to surmount these immense worldwide challenges than to hark back to the challenges Eunice Kennedy Shriver faced in intellectual disability in the late 1950’s in the United States.

We--the United States of America-- were then ourselves a “developing country” with respect to people with intellectual disabilities and their families. Inappropriate institutionalization, denial of educational

opportunity, rampant discrimination in employment and the denial of appropriate health care were norms, not exceptions.

The President's Panel on Mental Retardation was the clearing in the wilderness whereupon the foundation for the next half-century of progress in the field was established. Eunice Kennedy Shriver was the moving force in that effort just as she has been the soul and the moving force of the Special Olympics worldwide in the United States.

In this spirit, as one way to honor her legacy, the establishment of a "Eunice Kennedy Shriver Global Presidential Panel on Intellectual Disability" is proposed. Like President Kennedy's historic 1961-62 panel in which Mrs. Shriver played such a key leadership role, this new panel would propose programs for national action to address intellectual disability in participating developing countries and in the United States.

A Global Presidential Panel Report would be completed in celebration of and to coincide with the 50th anniversary of the original 1962 transmittal of the Kennedy panel's landmark final report. Hence, the report might be presented to President Barack Obama on October 16, 2012 at a White House event honoring the work of the global panel and the heads of state of the participating nations.

But make no mistake. Formidable challenges remain to be addressed here in the United States even given the overall growth of programs and funding for intellectual disability services in recent decades.

It is striking how inequitably distributed resources are to states, communities, families and individual consumers. Scores of thousands of persons with intellectual disabilities are on waiting lists.

Tens of thousands more inappropriately reside in state-operated institutions and nursing homes, notwithstanding the U.S. Supreme Court's Olmstead decision promoting access to community residential services and family support options to institutionalization.

Direct support staff wages in community facilities and in family homes are often at or below the poverty level.

Staff turnover is very high.

Family support programs receive only a small portion of funding in the field today; participation in supported employment programs nationally is declining; and many students with intellectual disabilities are still educated in segregated classes or separate educational facilities.

On top of these challenges, notwithstanding the new federally funded rehabilitation engineering research center on cognitive technologies announced this morning at this conference, there is very limited support for research and research training for facilitating the development, testing and diffusion of emerging cognitive technologies for people with intellectual disabilities.

Eunice Kennedy Shriver's legacy is unique worldwide in the history of the disability movement. It is in the spirit of stimulating discussion about how we might honor that legacy that this proposal for a Eunice Kennedy Shriver Global Presidential Panel on Intellectual Disability is presented. The program could be launched as an initiative within a to-be- established Eunice Kennedy Shriver International Center on Intellectual Disability.

The proposed panel draws on and builds from Mrs. Shriver's grand achievements with President Kennedy's panel, with the Kennedy Foundation, and with the International Special Olympics. It is a proposal presenting the best of the United States as a humanitarian and peaceful force on the world stage. Thank you.