

The President's Panel and The Public Policy Contributions of Eunice Kennedy Shriver

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AUTHOR'S NOTE: The language utilized in this paper includes the historical term "mental retardation", which is no longer acceptable professional terminology or appropriate language. Where this outmoded term is used it is in the context of accurately reflecting previous sources, and not meant to be either stigmatizing or hurtful, but rather a reflection of the historical period being described.

Eunice Kennedy Shriver was born on July 10, 1921, the third daughter and fifth child of Rose Fitzgerald Kennedy and Joseph P. Kennedy. After earning a BS in Sociology from Stanford University in 1943, she worked in the Special War Problems Division of the State Department, headed a juvenile delinquency project of the Department of Justice, and worked as a social worker with incarcerated women and in juvenile courts. In 1953 she married Robert Sargent Shriver.¹

Out of dedication to Rosemary Kennedy, the Kennedy's second daughter, a woman with intellectual disabilities and in memory of their first son Joe Jr., killed in World War II, the Kennedy family established the Joseph P. Kennedy Jr. Foundation in 1946

"To seek the prevention of mental retardation intellectual disability by identifying its causes and to improve the means by which society deals with its citizens who have mental retardation"²

In 1957, Mrs. Shriver became director of the Foundation, which was the only foundation in the country dedicated to people with intellectual disability. In 1958, Joseph P. Kennedy Sr. requested that Eunice and Sargent Shriver take responsibility for the Kennedy Foundation's new program in the prevention of intellectual disability. It is important to recognize the partnership Eunice Kennedy Shriver had with her husband

Sargent Shriver, both in their family life and the work of the Kennedy Foundation. In the oral history she provided to the Kennedy Presidential Library in Boston, Mrs. Shriver spoke eloquently of their partnership.³

Mrs. Shriver's ongoing collaborations with two other men were instrumental in supporting her contributions. Dr. Robert Cooke, the father of two children with significant disabilities, was the Chair of Pediatrics at Johns Hopkins School of Medicine when they began to work together. Dr. Cooke became the Kennedy Foundation's Scientific Advisor, influencing Mrs. Shriver to shift the focus of the Foundation from care and treatment to research. In the policy arena, much of Mrs. Shriver's impact was realized through her working with Myer "Mike" Feldman, an advisor to President Kennedy.

Mrs. Shriver's contributions, while greatly facilitated by her relationship to her brother President John F. Kennedy and her ability to enlist and build upon his support and concern for people with intellectual disability, were also a function of her personal qualities. Although she grew up in a family of wealth and privilege, that didn't mitigate her own commitment to hard work and disinterest in living a life of "only playing tennis and bridge". She was strategic in her thinking, in her actions, and in evoking the efforts and support of others. Possessed of laser like focus and perseverance, Mrs. Shriver was forceful and pragmatic. During the homily at her funeral, the priest recounted that during the wedding ceremony of her daughter Maria at which he was

officiating, he saw Mrs. Shriver signaling him from the first row where she was sitting. He realized she was sending him a message and silently mouthing the phrase, "Keep it moving...keep it moving".⁴

One of Mrs. Shriver's most enduring and endearing qualities was her respect, caring, and relationship with people with intellectual disabilities. This grew out of her family's love for her sister Rosemary, and exemplified by the day camp she started at her home in 1962. Arising from the directness of these valued relationships, one of Mrs. Shriver's most salient and often overlooked contributions was to enhance public understanding and acceptance of individuals with intellectual disabilities and to provide encouragement to families.

In 1962, Mrs. Shriver wrote an article for the Saturday Evening Post called "Hope for Retarded Children".⁵ Although what we now know as the ARC, then the National Association for Retarded Children, had been founded 12 years earlier at a joint meeting with what was then the American Association on Mental Deficiency (now AAIDD), Mrs. Shriver described the tremendous isolation of parents and the shock and shame of families having a child with intellectual disability. The Kennedys, as a family of wealth, status, and power within American life, acknowledgement of having a family member with intellectual disability brought mental retardation into the open. This was the beginning of the understanding of this condition as parallel to other human experiences.

“Like diabetes, deafness, polio or any other misfortune, mental retardation can happen in any family. It has happened in the families of the poor and the rich, of governors, senators, Nobel prizewinners, doctors, lawyers, writers, men of genius, presidents of corporations-the President of the United States”⁶

While this language may seem to us now as arcane or stigmatizing, we need to appreciate these statements in their historical context. Fifty years ago this represented a progressive and liberating breakthrough.

This article, appearing in a widely read, popular family magazine, akin to Life magazine, also tackled the subhuman conditions found in many large institutions and enunciated the importance of employment - a thread which ran through much of Mrs. Shriver's efforts over time and was truly prescient. Within our present context it is hard to appreciate the paradigmatic shift that this public expression about intellectual disability and the normative nature of disability represented in the article's assertion that “weary fatalism is not longer justified”.⁷ Mrs. Shriver created the historical antecedent and underpinnings for our understanding and appreciation, as enunciated in the Developmental Disabilities Act, championed by Senator Edward M. Kennedy that “disability is a naturally occurring part of the human experience”.⁸

Eunice Kennedy Shriver in fostering this different awareness, most significantly galvanized the creation of federal public policy addressing what we now call intellectual disability. With the world as we know it now, it is very difficult for us to imagine not only the stigma but the policy and service context of the 1950s and the early 1960s. Federal

research funding for intellectual disability in the early 1950s was very modest. Approximately four million dollars was dedicated to the National Institute for Neurology, Communication Disorders and Stroke and the National Institute for Mental Health, which was really only concerned with mental health not intellectual disability. The federal Department of Health, Education and Welfare - now split into the Department of Health and Human Services and the Department of Education, was not established until 1953. The Social Security Act, which now provides income maintenance for individuals with disabilities through Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), had not yet expanded beyond its original mandate as income maintenance for the elderly. While service systems now depend on Medicaid as health insurance for acute care for people with disabilities and as the basis for funding long term community and residential supports, it is hard to keep in mind that Medicare and Medicaid were not established until 1965.

The Joseph P. Kennedy, Jr. Foundation played an important role in pushing forward the development of national policy in two ways. First, by having previously funded Research Centers, the Foundation had concrete information and data about the structure and costs of such centers and programs. In today's parlance, the Foundation had developed models that needed to be taken to scale. The second and more long-term impact was Eunice Kennedy Shriver's realization, following the

1960 election of John F. Kennedy as President, that there was a need for broader action and resources, beyond the scope of what could be provided by the private resources of the Foundation. As a result of many conversations between Eunice and her father about the lack of national policy and focus, Joseph P. Kennedy Sr. declared

“This has been a terrible situation in the country. The foundation can’t go on trying to lick this problem alone; it’s impossible for us to do it. It affects too many families in the country”⁹

This declaration was the beginning of the transition from predominant reliance on private helping agencies and charities, to government involvement in addressing intellectual disability.

Mrs. Shriver asked her brother, President-elect Kennedy, to form a national committee to study the problem. He agreed, and that was the origin of the President’s Panel on Mental Retardation.

Elizabeth Boggs’ view was that as a Senator he was not involved in these issues¹⁰ or with the Massachusetts Association for Retarded Children ¹¹ (as it was called then), and that it was Eunice Kennedy Shriver who galvanized John F. Kennedy to address these issues as President. When Kennedy was elected President in November of 1960 it was Mrs. Shriver who urged making mental retardation a priority. The presidential transition task force recommended the establishment of the National Institute of Child Health and Human Development to conduct and support research on mental retardation as well as all aspects of maternal and child health and human development. Despite his affection

for their sister Rosemary, as President, Kennedy was skeptical about the need for another Institute. Mrs. Shriver's successful advocacy pointed out to her brother that no one was studying prenatal and perinatal health and if there had been, the President and his wife Jackie might not have lost their newborn son Patrick to inadequate lung development, a consequence of prematurity.

President Kennedy was also compelled by meeting The Mc Grath family¹² that had two daughters with phenylketonuria-PKU. Sheila, the older sister was intellectually impaired; Kammy, the younger one, who had access to the therapeutic diet was developing typically. This was a visible, dramatic example of the impact of intervention based on research and the dissemination of knowledge: the identification of the etiology of PKU, implementation of newborn screening and access to the therapeutic nutritional regimen. This family was the human exemplar of the potential of technologic and scientific solutions to intellectual disability, and contributed to President Kennedy making a commitment to this institute. Put in place in 1962 as part of NIH, that Institute has become the Eunice Kennedy Shriver Institute of Child Health and Human Development.

While she praised her brother President Kennedy's advocacy for resources, it was Mrs. Shriver who organized the political processes to guide that advocacy toward the development of meaningful public policy. As a result of Mrs. Shriver's persistence and advocacy in October 1961 President Kennedy held a press conference decrying

“the central problems of cause and prevention remain unsolved and I believe that we as a country in association with scientists all over the world, should make a comprehensive attack”

“it is my intention to appoint a panel of outstanding scientists, doctors and others to prescribe a plan of action in the field”¹³

The President's announcement vividly reflects the social context of the time: the possibilities and potential of science to address and conquer problems and cure conditions. His announcement reflects an historical period where potential seemed unlimited and space was the “new frontier”. This frontier spirit had an upbeat and aggressive “can do” attitude. The language included metaphors of combat: attacking and fighting the causes of mental retardation. The announcement was imbued with an international perspective, the belief that other countries had things to teach us. This was a uniquely post World War II consciousness, respecting the importance of other nations - a break from the isolationism of the late 1930s and unencumbered by nationalistic notions of the United States as the only source of knowledge or culture.

Mrs. Shriver was not a member of the panel, but was clearly the guiding force in its creation, its direction, and how those findings were translated into law and policy. She was listed in the report of the panel as a consultant. In her crucial role in developing the Panel's membership, Mrs. Shriver demonstrated her incisive thinking, her goal oriented focus and her enduring and relentless pragmatism. She posed a series of questions as her criteria for members. Did the person have any

background? Did the person have any imagination? Did the person have any ideas about the problem?

At a meeting at the White House on October 18, 1961, President Kennedy charged the 27 member panel with submitting a report by the end of 1962. The panel, chaired by Leonard Mayo, included Drs. Elizabeth Boggs, George Tarjan, and Richard Masland, and the respected legal scholar, David Bazelon. Organized into six Task Forces and having traveled and researched nationally and internationally, the panel delivered its report with 112 recommendations in October 1962, two months ahead of the required schedule.

The Panel struggled with a series of tensions in its work. The tension between a focus on research and a focus on social issues was an ongoing polarity. Elizabeth Boggs is credited with ensuring a focus on the development of comprehensive community services. The panel also emphasized education and the importance of trained teachers. Teacher training remained an enduring priority for Mrs. Shriver and one to which she directed the resources of the Kennedy Foundation over time, both for the US and abroad. Among the researchers on the Panel, there was a tension between those who were focused on basic research to prevent mental retardation/intellectual disability and those focused on research related to treatment and intervention. Mrs. Shriver, Dr. Cooke, and others were oriented to treatment and held the belief that clinical treatment services and programs should be research based, anticipating

our present day emphasis on evidence-based practice. Mrs. Shriver's pragmatism and strategic sense were again demonstrated by her recognition that although there were those on the panel who wanted to propose a more comprehensive basic research program, in effect a second NIH, "...it was impossible to do it anyhow. You just wouldn't have gotten anyplace".¹⁴

The outcomes and recommendations of the Panel addressed research, the training of personnel and employment. This resulted in a focus on employment for people with intellectual disabilities through the President's Committee on Employment of the Physically Handicapped. President Kennedy changed Civil Service laws to enable people with intellectual disabilities to work in the civil service system, and also hired an individual with intellectual disability to work in the White House. In part due to Sargent Shriver's role in national service, there was also a proposal for a "domestic peace corps" as a way of getting more people involved in working with individuals with intellectual disability.

Although a federal effort, the work of the Panel had a dramatic impact on state policy for people with intellectual disabilities. In August of 1963, based on the vision of its chair Leonard Mayo, the Panel sponsored a White House Conference on Mental Retardation, with a keynote by Sargent Shriver. With representatives invited from each state, the main purpose was to get states to set up a state Department of Mental Retardation. At that point 48 years ago, many of the states did

not have a governmental department addressing intellectual disability. Where states did have such a department, most were subsumed within the mental health bureaucracy.

From a federal policy perspective, the work of the President's Panel was expansive. Mrs. Shriver's focus was laser like and pragmatic, as evidenced in her description of the structure and intent of the report of the Panel:

“This report was written for consumption and passage as bills by the Congress. I knew what President Kennedy would support and what he wouldn't.....We wanted legislation passed, and that was always the aim of this report.”¹⁵

The Panel did not publicize its work meeting by meeting - an interesting contrast to the way some of our present committee and governmental structures function, emphasizing “sunshine laws” and public participation. Mrs. Shriver's was clear:

“.....we concentrated on just that one objective, to get the report and try to get hundreds of millions of dollars which were needed. What difference does anything else make really?”¹⁶

With the exception of Rhode Island's John Fogarty and a few other members, there had previously been little Congressional attention to intellectual disability. In Mrs. Shriver's view these issues were becoming attended to, and not because she was the President's sister. Her perception was that congressmen felt

“My God, this is something none of us have done anything about and we'll do something”

and she adds,

“And it was really very pleasant compared to anything that’s happened since”¹⁷

At the same time that federal mental retardation legislation was being crafted in early 1963, a federal mental health bill was also in the works. Wilbur Cohen, then Secretary of the Department of Health, Education and Welfare (HEW) suggested combining mental retardation and mental health into a unified bill. Mrs. Shriver, although initially concerned because of the history of intellectual disability always being subsumed and unaddressed by mental health (for which there were state entities), was reassured that mental retardation “taking the lead” would enhance the possibility of passage. Mrs. Shriver expressed her appreciation at the irony:

“I was pleased because mental retardation was always the underdog and now it was the leader”¹⁸

This legislative advocacy on behalf of individuals with intellectual disabilities also benefitted the programs which were initially “Crippled Children’s Services”, and are now Title V of the Social Security Act, the Maternal and Child Health Children with Special Health Care Needs programs.

As prelude, President Kennedy delivered a Special Message to Congress on Mental Illness and Mental Retardation, promising bold new approaches. On October 24, 1963 President Kennedy addressed the 13th annual meeting of the National Association of Retarded Children. On that day, in a now iconic photo, President John F. Kennedy handed Eunice

Kennedy Shriver the pen with which he had just signed the Maternal and Child Health and Mental Retardation Planning Amendments to the Social Security Act, the first major federal legislation to “combat mental illness and retardation”. This provided for planning grants for states to update intellectual disability programs and also funding for the prevention of intellectual disability through maternity and infant care. A week later, on October 31, 1963, President Kennedy signed the Mental Retardation Facilities and Construction Act. This legislation provided for facilities for the prevention, care and treatment, research centers, university related diagnostic centers and teacher training funds. These were the precursors to the original University Affiliated Facilities, now University Centers for Excellence in Developmental Disabilities Education, Research, and Service.

Eunice Kennedy Shriver, with vision, drive, and pragmatism, coupled with expertise, information, access, and strategic action, enabled President John F. Kennedy to express the new ideal that

“the mentally ill and the mentally retarded need no longer be alien to our affections or beyond the help of our communities”¹⁹

Historical Postscripts:

1966: President Lyndon B. Johnson signed Executive Order 11280, formally establishing the President's Committee on Mental Retardation (PCMR).

2003: President George W. Bush signed Executive Order 13309, renaming the President's Committee on Mental Retardation to the President's Committee for People with Intellectual Disabilities (PCPID).

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1

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¹²

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¹³ Ibid

¹⁴ Eunice Kennedy Shriver, Oral History Interview-JFK#1, 5/7/1968, p.15

¹⁵ Ibid, p.14

¹⁶ Ibid, p.11

¹⁷ Ibid, p.22

¹⁸ Ibid, p.22

¹⁹

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