Perspectives

Honoring Eunice Kennedy Shriver's Legacy in Intellectual Disability

David Braddock

DOI: 10.1352/1934-9556-48.1.63

Eunice Kennedy Shriver: 1921–2009

An entire book needs to be written to do justice to the many achievements of Eunice Kennedy Shriver in philanthropy, public policy leadership, and the International Special Olympics movement. However, my task here is to briefly highlight Mrs. Shriver's most significant and lasting achievements in the field of intellectual disability as they relate to these three spheres of activity. Her striking achievements, spanning more than 50 years, involved formidable challenges and changed the field of intellectual disability forever by advancing human dignity and civil rights, public acceptance, community services, research, health promotion, and the joy and benefits of physical activity and sport.

What Eunice Shriver Faced

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 (2000), 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 (NIH) National Institute on Child Health and Human Development (NICHD)—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 the field of 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 notable exceptions of Congressman John Fogarty (Democrat, RI) and Senator Lister Hill, (Democrat, AL), in the U.S. Congress. The late Elizabeth

Boggs cofounded the National Association for Retarded Children in 1950 and in 1958 was elected its first female president. Three years later she would be a leading member of President John F. Kennedy's Panel on Mental Retardation. "In the mid 1950's," she wrote, "NIMH [National Institute of Mental Health] staff [at the National Institutes of Health] privately doubted if as much as $250,000 could be well spent on a subject as unglamorous as mental retardation" (Boggs, 1971, p. 107).

The federal presence in intellectual disability had been so modest in the early 1950s that a grant from the Kennedy Foundation of $1.25 million to establish a private school in Illinois exceeded the entire federal budget for intellectual disability services at that time (*New York Times*, 1952). In 1956, "There was not an identifiable program [for services] in the federal government aimed at meeting the problem of mentally retarded children" (U.S. House of Representatives, 1963). By 1958, total federal support for intellectual disability research was still just $4.3 million annually. It was almost exclusively administered by the National Institutes of Health's NIMH and the National Institute of Neurological, Communicative Disorders and Stroke (NINCDS).

However, there would be signs of change. In 1958, then-fledgling Congressman George McGovern of South Dakota sponsored what became Public Law (P.L.) 85-926, the Education of Mentally Retarded Children Act. This statute authorized a modestly funded $1 million training program for teachers of children with intellectual disabilities. The enactment, according to Elizabeth Boggs (1971), responded to the fact that enrollment of children and youth in special education programs had grown nationwide by 150% during the preceding decade. More special education teachers were needed, and they required specialized training. McGovern's legislation was the predecessor of contemporary special education personnel preparation programs. The precedent-setting Education for All Handicapped Children Act of 1975 (P.L. 94-142), the foundation of today's Individuals With Disabilities Education Act (IDEA) as amended, would not become law for another 17 years after McGovern's 1958 legislation.

For adults with intellectual disabilities in 1958, federal grant support for services was essentially restricted to the state–federal vocational rehabilitation grant program. That fiscal year, only 1,578 persons with intellectual disability were reported to be rehabilitated (i.e., placed in jobs) under the auspices of that program across the entire nation. This was 2% of the overall rehabilitation caseload in the states for persons with disabilities of all types. In 2006, the rehabilitation caseload of people with intellectual disabilities was 28,602 persons, 14% of the overall disabilities caseload nationally.

Power to the States

The U.S. Supreme Court ruled in 1954 in *Brown v. Board of Education of Topeka, Kansas* that separate educational facilities segregated by race were inherently unequal and violated the 14th Amendment to the U.S. Constitution. In the 1970s, the 14th Amendment's due process provision was interpreted to apply to people with intellectual disabilities who were inappropriately institutionalized in large state-operated facilities (Herr, 1983). However, in 1954, 173,594 people with intellectual disabilities, many of them children, remained separated from children and adults without intellectual disabilities, in poorly funded, state-operated residential "schools" and in state psychiatric institutions across the country (NIMH, 1956). To say that these facilities were spartan would be too kind. Mrs. Shriver wrote in a 1964 *Parade Magazine* article, after touring 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" (pp. 6–7). The "sights" she saw were even more vividly summarized in a moving passage she had written two years earlier for the September 22, 1962, edition of *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. In the words of one expert, such unfortunate people are "sitting around in witless circles in mediaeval prisons." This is all the more shocking because it is so unnecessary. Yet institutions such as these still exist. (p. 72)

In 1967, five long years after *The Saturday Evening Post* article appeared, Niels Erik Bank-Mikkelsen, national director of Denmark's intellectual disability services programs, toured Cali-

fornia's Sonoma State Hospital, which at the time had 3,400 residents with intellectual disabilities. "I couldn't believe my eyes," he said. "It was worse than I have seen in visits to a dozen countries. In our country, we would not be allowed to treat cattle like that" (National Association for Retarded Children, 1967b, p. 2). The disclosure of these conditions was not a surprise to the field nationally. A year before Bank-Mikkelsen's comment was widely distributed in the media, Professor Burton Blatt, then at Boston University, and photographer Fred Kaplan, published *Christmas in Purgatory* (1966). An excerpt from this powerful photographic essay on institutional conditions in America was reprinted in *Look Magazine* (Blatt & Mangel, 1967). The graphic photos stirred national attention.

However, very difficult impediments in funding intellectual disability services in the states persisted. "States rights" dominated the landscape of federal–state relations. "The powers not delegated to the United States by the Constitution are reserved to the States respectively or to the people." So reads the 10th Amendment to the U.S. Constitution, thus relegating virtually exclusive oversight of state-operated intellectual disability institutions to state governments, which had very limited tax bases at the time. To illustrate how fiscally neglected state institutions were in the 1960s, the President's Panel on Mental Retardation stated in its 1962 report to President Kennedy that it was "gratified" to learn that average spending per resident in these facilities advanced from $2.05 per day in 1950 to $4.55 in 1960 (p. 132).

State-operated institutions would not begin a steady national decline in their resident populations until after they peaked in 1968, six years after President's Kennedy's panel recommendations were issued. (The resident population of institutions has declined every year since then by between 3% and 6%.) In 1971, federal class action litigation in the states on rights to education and habilitation, stimulated by the advocacy of parents and concerned professionals, provided catalysts for community integration and access to education. Today, 11 states operate residential service delivery systems without reliance on state-operated institutions for people with intellectual disabilities. The vast majority of the 533,000 persons with intellectual disabilities living in supervised "out of home" residential settings nationally, including institutions, now live in community settings with only a few other persons. The 2009 institutional census of state-operated institutional facilities is estimated from projections of 2007 and earlier data to have fallen below 37,000 persons nationally (Braddock, Hemp, & Rizzolo, 2008).

The President's Panel on Mental Retardation and Eunice Kennedy Shriver's Leadership

Eunice Shriver's most catalytic and lasting contribution to the community integration and institutional reform movement was her leadership in 1961 in championing the creation of the President's Panel on Mental Retardation and in subsequently playing "an active role pressing for ever-increasing vigor in the panel's performance" (Boggs, 1971, p. 113). Shriver insisted that only the finest leaders, scientists, and clinicians be appointed to the panel. Panel members included the aforementioned Elizabeth Boggs and Robert Cooke, pediatrics chair at Johns Hopkins University, Kennedy Foundation scientific adviser, and noted administrator. Cooke had led the call for the creation of an NIH "kiddie institute," which became the NICHD in 1962. A parent advocate for two children with cri du chat syndrome, he was instrumental in convincing Mrs. Shriver to shift the focus of the Kennedy Foundation from care and treatment to research into causes.

Other key panel leaders included Leonard Mayo, chair of the 1950 White House Conference on Children and Youth, who chaired the panel, and George Tarjan, the panel's vice chair, a psychiatrist and superintendent of the Pacific State Hospital in California. In 1959, Tarjan was president of the American Association on Mental Retardation (now the American Association on Intellectual and Developmental Disabilities) and was president of the American Psychiatric Association during 1983–1984.

Boggs, who held a doctorate in mathematical chemistry from Cambridge University, was a leader of the panel's Task Force on Coordination as well as vice chair of the Task Force on Law. Boggs later wrote, "The idea of the panel was urged on the president by his sister Eunice Shriver" (Boggs, 1971, p. 112). Donald Stedman and John Throne, directors of the Kennedy Foundation during the early 1960s, both concurred with Boggs' assessment

of Eunice Shriver's personal advocacy role with the president to establish the panel (Shorter, 2000, p. 84).

After the panel was established, Shriver personally and passionately lobbied her brother, the president, and his capable long-time aide Myer (Mike) Feldman, as only she could, to generate critical presidential support for the panel's 97 recommendations. Although she was not a formal member of the panel, she was the only consultant listed in the panel's final report to the president. Feldman, now deceased, was a brilliant attorney who had also served as an aide to Kennedy in the Senate and would later serve as Kennedy's presidential aide and as counsel to President Lyndon B. Johnson. He became one of Mrs. Shriver's closest friends, and, for many years, Feldman was vice chairman of the board of directors of the International Special Olympics.

President Kennedy's October 1961 *White House Statement on Mental Retardation*, delivered in the Rose Garden, was likely written by Feldman as a call to action, in the president's voice:

> The manner in which our Nation cares for its citizens and conserves its manpower resources is more than an index to its concern for the less fortunate. It is a key to its future. Both wisdom and humanity dictate a deep interest in the physically handicapped, the mentally ill and the mentally retarded. Yet, although we have made considerable progress in the treatment of physical handicaps, although we have attacked the problems of mental illness, although we have made great strides in the battle against disease, we as a nation have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected. (President's Panel on Mental Retardation, 1962, p. 196)

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. The panel 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 large cities, sought technical assistance from a variety of governmental and nongovernmental sources, and traveled to review facilities in Sweden, Denmark, Holland,

President John F. Kennedy hands Eunice Kennedy Shriver the pen he used to sign groundbreaking intellectual disability legislation in October 1963. The legislation implemented recommendations of his presidential panel (photo from the author's collection).

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 the unfolding crisis to the panel as he met with them (Boggs, 1971, p. 107).

As Close as Possible

One overarching theme could be identified in the panel's final report, entitled *National Action to Combat Mental Retardation*: that future services and supports to 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. Over 175,000 individuals with intellectual disabilities were institutionalized in large, state-operated intellectual disability residential facilities at the time (U.S. Bureau of the Census, 1975). Many individual facilities had thousands of residents. The Willowbrook State School in New York, for example, reached a peak of approximately 8,000 residents. State-operated psychiatric hospitals for persons with mental illness also housed an additional 37,000 persons with intellectual disabilities nationally in their massive general populations (NIMH, 1961).

The President's Panel on Mental Retardation issued 97 recommendations emanating from its six task forces. Many were subsequently embodied in P.L. 88-156, the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, and in P.L. 88-164, the Mental Retardation Facilities and Community Mental Health Centers Construction Act. Both were enacted just a few weeks prior to the president's death in 1963 and both were noteworthy legislative achievements. P.L. 88-156 doubled the fiscal authorization level for the existing federal maternal and child health state grant program and authorized special grants under Section 508 for maternity and infant care "to help reduce the incidence of mental retardation caused by complications associated with childbearing."

P.L. 88-164 authorized three interrelated construction programs. Under Title I, Part A, $27 million was expended for the construction of Mental Retardation Research Centers affiliated with large universities at 12 sites. Title I, Part B authorized construction of 18 university-affiliated facilities (UAFs), now termed the University Centers of Excellence in Developmental Disabilities Education, Service and Research (UCEDDs). A community facilities construction program was also authorized under Title I, Part C. Between 1965 and 1970, 362 projects involving $90 million were completed for construction of facilities for the diagnosis, education, treatment, training, and personal care of people with intellectual disabilities (Braddock, 1987). The Kennedy Foundation provided the matching grants for numerous original applicants for the UAF grants and several applicants for the research centers. Thus, many of these university centers are named in honor of Eunice Kennedy Shriver and John F. Kennedy. The United States is unique internationally in the breadth, depth, and sheer numbers of UCEDD programs. At present, there are 67 UCEDDs, including at least one in every state, and 21 intellectual and developmental disabilities research centers.

It is notable that P.L. 88-156 legislation also called for the first comprehensive, state-by-state planning in intellectual disability services. This was an important action because it began to penetrate the wall of indifference between federal and state governments regarding institutional conditions and the general lack of educational, rehabilitative, medical, and community residential services in all the states. The state planning objectives were the forerunner of comprehensive, multiagency developmental disabilities planning in the states subsequently authorized in 1970 in the Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517). That comprehensive planning mandate continues to this day. The late U.S Senator Ted Kennedy was an original prime sponsor of the legislation in the Senate.

Thus, in 1963, the federal government's expectation of the reform of intellectual disability services across the states was initiated for the first time in the nation's history. The field would never be the same. The President's Panel on Mental Retardation had been a catalyst for change, but the principal change agent was someone who was not a formal member of the panel: Eunice Kennedy Shriver. Her leadership of the panel in the Office of the President and with the president personally made all the difference. The panel's productivity was a tribute to all its citizen members and to President Kennedy. However, the panel was Eunice Kennedy Shriver's first great and lasting triumph in

the intellectual disability field. In November 1966, she would be honored with the prestigious Lasker Public Service Award in Health. The citation read:

> Undaunted by public apathy and ignorance, Mrs. Shriver has, in the last few years, focused public attention on the problems of the mentally retarded and accomplished a revolution in research on the causes of mental retardation, the care of the retarded, and the acceptance of the retarded by family and community. (National Association for Retarded Children, 1967a, p. 1)

Eunice Kennedy Shriver never rested on laurels. She would receive many awards in her career, in addition to the Lasker, including, to name a few, the Humanitarian Award from the American Association on Intellectual and Developmental Disabilities; honorary degrees from Yale, Princeton, Georgetown, and numerous other universities; the Presidential Medal of Freedom from President Ronald Reagan; the French Medal of Freedom; the National Collegiate Athletic Association (NCAA) Theodore Roosevelt Award; and the Laetare Medal from the University of Notre Dame. In 2008, she received the inaugural Sportsman of the Year Legacy Award from *Sports Illustrated*. Two years after receiving the Lasker Award in 1966, one of her first major awards, she promptly launched an enterprise that would have an unprecedented worldwide impact in the field of intellectual and developmental disabilities: the Special Olympics.

Emergence of the International Special Olympics

The President's Panel on Mental Retardation was unprecedented in the history of the intellectual disability field in the United States. However, Eunice Shriver's leadership had only just begun in intellectual disability. On July 20, 1968, 900 Special Olympians from 25 states and Canada gathered at Soldier Field in Chicago, Illinois. By that time, Mrs. Shriver had interacted for several years with key leaders in the emerging field of adapted sports for people with intellectual disabilities. The group included the Canadian adaptive sports innovator and professor Frank Hayden, the late Professor William Freeberg of Southern Illinois

Launching the Special Olympics: 1968, Eunice Kennedy Shriver overlooks Chicago's Soldier Field at the first national Special Olympics games (photo courtesy of International Special Olympics).

University, and Ann McGlone Burke, then of the Chicago Park District and now a justice on the Illinois Supreme Court. According to the biographer Edward Shorter (2000), Mrs. Shriver first called for "a national tournament of athletic contests in the United States among teams of mentally retarded children" (p. 128) in 1965, while speaking in Dallas. "Camp Shriver," a summer sports activity event for children with intellectual disabilities, was first held at the Shriver's Timberlawn home in Maryland beginning on June 7, 1962. Camp Shriver subsequently expanded to numerous additional sites and, most recently, to Nairobi, Kenya.

In Chicago, at the first national games, Eunice Kennedy Shriver would announce a "Special Olympics training program for all mentally retarded children everywhere" (Shorter, 2000, p. 134). Four decades later, in 2009, more than 3.1 million athletes and over 1 million volunteers and coaches from 175 countries would be participating. In many of the world's poorest countries, Special Olympics is a very important development program for people with intellectual disabilities. In the past 13 years, with Timothy Shriver's leadership as chief executive officer and Mrs. Shriver's continuing inspiration as the founder, the Special Olympics has emerged as the leading sports participation and health-promotion development program for people with intellectual disabilities in the developing 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 early and mid-1960s 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, and then throughout the world. However, this is another story, a glorious story of the triumph of one determined woman who led millions of Special Olympians into the modern era and gave them and their families pride to be alive, engaged, and active in body, mind, and spirit. Mrs. Shriver's leadership experiences with the Kennedy Foundation and with the president's panel were put to extraordinarily good use on the world stage through the Special Olympics.

Eunice Kennedy Shriver's personal qualities were just as important in her success and a key to understanding her achievements in the intellectual disability field and in leadership generally. To paraphrase her son Timothy Shriver, 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. These 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. The impact of that citizen activism can be characterized by political philosopher John Stuart Mill's (1862) adage that "one person with a belief is equal to a force of ninety-nine who have only interests" (p. 23). In Eunice Kennedy Shriver's case, Mill's adage is an understatement. Shriver spoke with the force of millions in empowering the voices of people with intellectual disabilities and their families around the world. She lived by action, not adage.

Honoring Her Legacy

How do we properly honor Eunice Kennedy Shriver's dedication and leadership in the field of intellectual disability? What goals would she ask us to articulate and address more effectively in the future if she could do so today? Those who knew her might say that she would insist that we continue to support vigorously rights and opportunities for people with intellectual disabilities and their families and that we acknowledge that there is much to do in the United States and in other developed countries to provide better inclusive education and health care and to promote healthy lifestyles, to enhance opportunities for social and employment participation, and to more aggressively level the playing field through improved access to emerging assistive technologies for all people with cognitive disabilities (Rizzolo & Braddock, 2008).

Mrs. Shriver would also remind us that the greatest challenge in intellectual disability of this

2007 Special Olympics World Games, Opening Ceremony, Shanghai, China. Photo courtesy of Special Olympics, by Diego Azubel.

generation, and likely the next, lies in recognizing and acting on the fact that the 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, and personal support. Special Olympics organizations are typically among the most viable nationwide organizations explicitly dedicated to improving the lives of people with intellectual disabilities in these poor countries and they often have excellent access to the business community and government leaders.

Forging stronger partnerships between country-based Special Olympics programs and intellectual disability–related, nongovernmental organizations, such as Inclusion International and local consumer and professional associations, would promote broadly based development of general services and supports for people with intellectual disabilities, and for Special Olympics programs. Potential impacts include the expansion of programs promoting health, social and educational participation, community acceptance, and employment. In addition, the university-based UCEDD model in the United States, launched by the president's panel initiative in 1963, and described previously, holds promise in the developing world as a possible model for advancing personnel training, clinical services, community and family support programs, and applied research in intellectual and developmental disabilities.

There is no stronger source of inspiration available to surmount these immense worldwide challenges than to reflect back on the challenges Eunice Kennedy Shriver faced in intellectual disability in the late 1950s in the United States. We—the United States of America—were then ourselves a "developing country" attitudinally and in failing to provide decent services and supports for 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 the norms, not exceptions, in the 1950s. The President's Panel on Mental Retardation was the clearing in the wilderness, whereupon the foundation for the next five decades of progress in the field was established in the United States. Eunice Kennedy Shriver was the primary moving force behind that effort, just as she has been the soul and the moving force of the Special Olympics worldwide.

Formidable challenges remain to be addressed here in the United States, even given the overall growth of support for intellectual disability services in recent years. However, it is striking how inequitably distributed resources are to states, communities, families, and individual consumers. Thousands of persons with intellectual disabilities are on waiting lists for community services and family support (Lakin & Turnbull, 2005). Tens of thousands more reside inappropriately in state-operated institutions and nursing homes, notwithstanding the U.S. Supreme Court's *Olmstead* (1999) 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 below the poverty level. Staff turnover is unacceptably high and often exceeds 50% (U.S. Department of Health and Human Services, 1999). Moreover, 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. In addition, there is very limited support for intellectual disability research and research training, as well as for the development, testing, and diffusion of emerging cognitive technologies for people with intellectual disabilities (Braddock, 2007).

Eunice Kennedy Shriver stimulated considerable progress in intellectual disability worldwide during her lifetime. She leaves at least three distinct and enduring legacies in intellectual disability as a guide. First is the 1961–1962 President's Panel on Mental Retardation and its catalytic national agenda in residential and community services, biomedical and behavioral research, education and training, and the prevention of intellectual disability. The 50th anniversary of the presentation of the panel's final report to President Kennedy in the White House will be October 16, 2012. We should celebrate that event and, if invited to do so, assist other nations to launch their own action-oriented panels to stimulate program development in intellectual disability.

The second legacy of Eunice Kennedy Shriver is her half century of leadership of the Kennedy Foundation's path-breaking philanthropy in education, research, and public service in intellectual disability. The foundation has been a beacon of light for many other foundations in the United States that have followed its lead and invested in the field of intellectual and developmental disabilities.

Mrs. Shriver's third legacy is the International Special Olympics and its breathtaking growth to over 3 million participants in 175 countries in 2009. Special Olympics is a leading development organization concerned with intellectual disability in all of these countries. Increasing numbers of athletes today are participating in Special Olympics–sponsored health assessment, medical–dental referral programs, and unified sports with nondisabled friends.

These three multifaceted legacies—the president's panel, the Kennedy Foundation, and the Special Olympics—are each themselves major contributions to the field of intellectual disability over the past half century. The task before us now is clear: Envision and create a better future for people with intellectual disabilities and their families than even Eunice Shriver could have imagined during her long and consequential lifetime.

So, in every country across the globe, in every city, town and remote village—and she touched almost all of them during her life—let the word go forth to honor the legacy of Eunice Kennedy Shriver.

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Author:
David Braddock, PhD (E-mail: braddock@cu.edu), Associate Vice President, University of Colorado System; Executive Director, Coleman Institute for Cognitive Disabilities; and the Coleman-Turner Chair and Professor in Psychiatry, University of Colorado, Denver, School of Medicine.

