

Perspectives

Presidential Address 2011

Imagining the Future: Establishing a New Legacy for AAIDD

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It is my privilege to close the 134th meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD) with a few thoughts about our association's legacy and the role each of us can take in shaping that legacy. In the past year we have lost two members of the Kennedy family, Senator Edward Kennedy and Ms. Eunice Kennedy Shriver, whose legacy in our field has been significant. In 1960, President John F. Kennedy, with the urging of Ms. Shriver, established the President's Panel on Mental Retardation (Figure 1), which included Dr. George Tarjan, president of this association from 1959 to 1960. The panel issued 97 recommendations, many of which formed the basis for legislation and funding streams that benefit people with intellectual disability and their families to this day. Only weeks before his assassination, President Kennedy signed legislation taking this nation's first steps toward a community-based system of supports (see Figure 1) and then spoke with members of The Arc about that historic legislation (see Figure 2).

In 1965, another Kennedy sibling, Senator Robert F. Kennedy, toured the Willowbrook State School on Staten Island. Afterwards, the visibly shaken senator addressed the press, decrying the state of conditions in which the inmates of Willowbrook lived:

I think that particularly at Willowbrook, we have a situation that borders on a snake pit, and that the children live in filth, that many of our fellow citizens are suffering tremendously because of lack of attention, lack of imagination, lack of adequate manpower. There is very little future for these children, for those who are in these institutions. (cited in Minnesota Developmental Disabilities Council, n.d.).

The Kennedy legacy in our field has been profound; the actions of these Kennedy siblings—who were compelled to act by their devotion to their sister, Rosemary—left a tangible legacy of community-

inclusion and civil rights for people with intellectual and developmental disabilities for which we, today, owe a great debt.

The AAIDD, of course, has its own legacy, both intertwined with and separate from the legacies of the Kennedy family. That legacy began on June 6, 1876, when seven men, all physicians and superintendents of training schools and institutions for people with intellectual disability, met at the Pennsylvania Training School in Media, Pennsylvania, to form the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons. The first meeting at which professional papers were presented, as they have been every year since, was June 12 to 15, 1877, at the Ohio institution in Columbus.

Those who know the history of our field and the history of the institutions at which many of these founders worked also know that the legacy of these facilities and a portion of the legacy of our association is a checkered one. But one should also know that the legacies of many of these founders were, in many ways, as important as those of the Kennedy family. For example, our first president, physician Edouard Seguin (Figure 3) can rightfully be called the Father of Special Education, having, in the early 1800s, created the first systematic and programmatic efforts to educate people with intellectual disability. The text he wrote on his system (*Traitement Moral, Hygiène, et Education des Idiots* [*The Moral Treatment, Hygiene, and Education of Idiots and Other Backward Children*] published in 1846 and translated into English in 1866), became the manual for social reformers, like the founders of the association, to establish schools for people who, previously, were abandoned to their fates in alms houses or poor houses. In fact, Seguin's work inspired Italian educator Maria Montessori.

Another of the founders, Dr. Hervey Wilbur (Figure 4), who succeeded Seguin as the second



Figure 1 Photograph of meeting of Lederberg and other members of the President’s Panel on Mental Retardation with President John F. Kennedy, October 18, 1961. (U.S. National Library of Medicine. Photograph is in the public domain.)

president, established, in 1848, the first school in America for people with intellectual disability in his own home in Barre, Massachusetts.

Of course, the AAIDD legacy has been added to and refined by leaders and members in the post-World War II era. To illustrate the significant role played by the association, its members, and leaders in the modern era, consider the legacy of the president of the association during its 100th anniversary year, Dr. Burton Blatt (Figure 5). A decade before serving as president, and compelled by Robert Kennedy’s pronouncements about Willowbrook and similar institutions, Blatt arranged to tour five institutions and brought with him photographer Fred Kaplan, who surreptitiously snapped photographs of the horrific conditions in these facilities. The resulting photoessay, entitled *Christmas in Purgatory*, juxtaposed stark and startling black and white photographs of inmates or rows of iron beds with children confined to them with poetry verses and essays selected by Blatt, beginning with the words: “There is hell on earth and in America there is a special inferno. We were visitors there during Christmas, 1965” (Blatt & Kaplan, 1966, p. v).

Burton Blatt’s legacy—and, rightfully, I think, part of the AAIDD legacy as well—is one of

championing the cause of basic human rights, dignity, and community inclusion. *Christmas in Purgatory* catalyzed the deinstitutionalization movement and, along with the federal focus on community services begun by President Kennedy and Ms. Shriver, ushered in the independent living and community supports era.

So, what will our legacy be to future generations? What will or can we, individually but more importantly as an association, do that will have the kind of impact that our predecessors have had? In considering this, I want to return to Senator Robert Kennedy’s comments to the press in 1965 after touring Willowbrook.

What has always struck me most about Senator Kennedy’s statement was his list of reasons that, in his words, “children were living in filth and our fellow citizens were suffering tremendously.” As one such cause, Senator Kennedy cited a lack of attention. I take that to mean the lack of societal attention: the responsibility of citizens of our nation and of caring people to pay attention to the needs of members of our society who are at the greatest risk for discrimination and maltreatment. It refers to attention from legislators and policymakers as well as attention from average citizens. We can



Figure 2 President John F. Kennedy addresses the 13th Annual Convention Luncheon of the National Association for Retarded Children on October 24, 1963, at the Mayflower Hotel, Washington, DC. (Photograph from the author's private collection.)



Figure 3 Edouard Seguin, MD, Founder and President (1876–1877) Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons. (Image from *Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons*, 1880, p. 1.)

relate to this issue: it is with us yet today; we continue to have to fight and advocate for more attention to and for people with intellectual and developmental disabilities.

Senator Kennedy also cited lack of manpower as a cause. There were too few people working in Willowbrook that day he toured, and there are too few people and resources committed to people with intellectual and developmental disabilities and their families today. We are aware of the critical issues associated with recruiting and retaining direct support professionals to support people to live better lives, issues related not only to recruitment and retention, but to the quality of the lives of such workers, who earn meager wages.

But, I wonder if many of us would wholly embrace the third reason given by Senator Kennedy on that day as he stood outside Willowbrook. There it is, right there between the familiar issues of lack

of attention and resources: *lack of imagination*. Lack of attention and lack of manpower—those were indictments of the system, of government, of society, and of others, by and large. Lack of imagination? That sounds like an indictment of our efforts, quite frankly.

I am certain no person in our association wants his or her legacy, or that of the association, to be characterized by future generations as evincing a lack of imagination. So what can we do to ensure that this is not the case? Individually, certainly, there are some members of our association who may leave a legacy to rival Edouard Seguin or Burton Blatt; but if we are honest, the truth is that few of us will do so. The problems are so big; our resources, energy, and time so limited—what can we really expect to achieve?



Figure 4 Hervey Wilbur, MD, Founder and President (1877–1888), Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons. (Image from *Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons*, 1886, p. 290.)

That is why this association is critical in my professional life and why I think it is critical in your professional life as well. If you or I want to leave a legacy that matters, a legacy of better, richer, fuller lives for people with intellectual and developmental disabilities, then I would argue that your chances of doing so are much greater within the AAIDD than on your own. Why join AAIDD? Why give of your limited time and resources? Fundamentally, I believe, it is because within AAIDD we—you and I—can leave a legacy that far exceeds that which we might leave individually.

Let me mention two examples of how this association is creating a legacy that is fundamentally altering our field. One of our legacies, clearly,

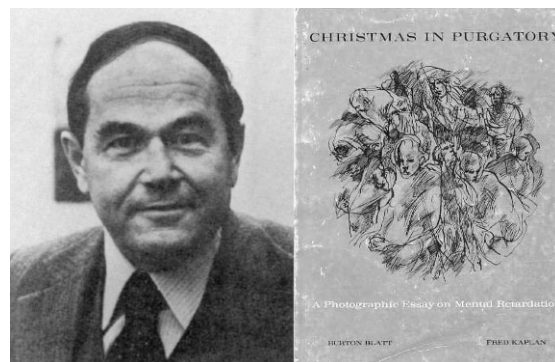


Figure 5 Photo of Burton Blatt. (Reprinted with permission of Center on Human Policy, Syracuse University.)

is our role in conceptualizing and defining the constructs that are used in our field. Since 1911, the association has provided leadership in conceptualizing the construct and providing guidance for diagnosis and classification (Figure 6). Again, the legacy of the use of diagnosis and treatment is mixed, intertwined with the legacies of institutions and discrimination I discussed previously; but these efforts also provide the association with an opportunity not only to reflect practice in diagnosis and classification but to change such practices. Recently, the association released the 11th edition of its influential terminology and classification manual (Schalock et al., 2010). The impact on the field of this effort, carried out by members who volunteer their time and talent, is significant. In the 9th edition (Luckasson et al., 1992), the Terminology and Classification task force, led by past-president Ruth Luckasson, introduced a fundamental shift in the way in which intellectual disability was understood, and with the 11th edition, under the leadership of past-president Robert Schalock, that shift comes full circle with the adoption of the term *intellectual disability*.

You may think that the change in terminology to intellectual disability is just pro forma and, to some degree, yesterday's news. But, the change to the term *intellectual disability* in the 11th edition of the manual is not just the adoption of yet another term; the change in the term better communicates and captures the radically different way of understanding disability introduced in the 1992 manual, as a way from being a problem that resided within a

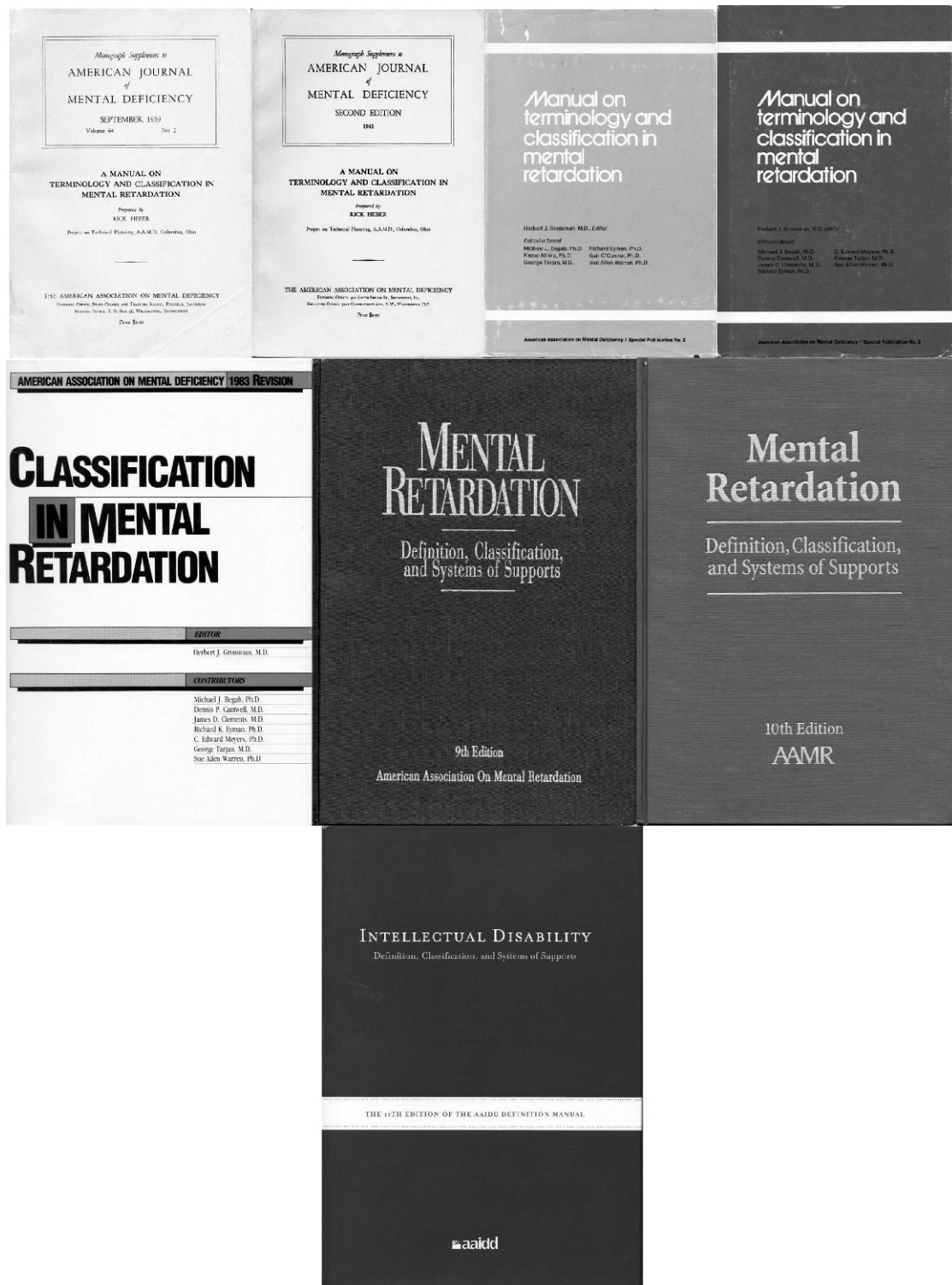


Figure 6 Terminology and classification manuals from 1959 to 2010.

person and, instead, focusing on the fit between a person's capacities, strengths, and the demands of the context in which he or she might live, learn, work, or play. This understanding, in turn, introduces a supports model that challenges us to use our imagination to figure out not only how to increase personal capacity, but also to modify the environment and context and to put in place supports that will enable people to function successfully in typical environments.

A second example of how our association's efforts are impacting the field involves the development and wide adoption of the AAIDD Supports Intensity Scale (Thompson et al., 2003). Frustrated that the fundamental changes introduced in the 1992 manual on how intellectual disability should be understood were not being adopted, former AAIDD Executive Director Doreen Croser asked Robert Schalock to spearhead an effort to create an instrument that would measure levels of support needs and provide an instrument or a tool that might propel the adoption of the understanding of intellectual disability introduced in 1992. Under the leadership of committee chairperson Jim Thompson, over a 5-year period, a task force of AAIDD members designed and evaluated the Supports Intensity Scale.

The development and implementation of the scale has provided a catalyst for fundamental changes in practice in our field. Through the leadership of Doreen and national staff in the publications department, particularly Bruce Applegren and Anu Prabhala, the SIS has been adopted by 15 states and Canadian provinces for use in making decisions about resource allocation and supports provision, is being considered for adoption by another dozen states or provinces, and has been translated into more than a dozen languages for use in numerous other countries. Why? Because the SIS changes the focus of evaluation; it measures the pattern and intensity of supports necessary for a person to participate fully in activities linked with normative human functioning; it aids in the funding and design of supports that not only enhance individual functioning, but promote the development, education, interests, and personal well-being of an individual. The SIS asks users to imagine what type, intensity, and duration of supports will be needed for a person to function successfully in all aspects of his or her life: in meaningful work experiences, in community living, in establishing friendships and meaningful relationships, and in living a better life.

I have worked enough with the SIS to believe that there is really only one thing that will limit the potential of these innovative advances for fundamentally changing how we do business and that is lack of imagination: the lack of imagination to envision how a person with an intellectual or developmental disability who has never had the opportunity to work can be provided supports that enable him or her to work alongside peers without disabilities; the lack of imagination to envision the types of supports that would enable a student with intellectual disability to be successful in postsecondary education; the lack of imagination to envision what types of supports would enable a person with intellectual disability to live in his or her own home.

So, what can you, as an AAIDD member, do to contribute to leaving a legacy of respect, dignity, value, and worth? If you do not know it already, here is the AAIDD mission: *To promote progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities.* We have also adopted a set of principles that guide our work and that help us achieve our mission. So, first, be cognizant of our mission and these principles. They are the means by which our legacy will be built. We are a big tent; our strength is that there is no other multidisciplinary association focused on issues that seek to improve the lives of people with intellectual and related developmental disabilities that has the capacity to act on such issues. I genuinely doubt that there is a single worthy objective—whether research, practice, or policy-focused—that cannot be accommodated within our mission and principles.

But it will take more than just awareness of a set of principles or a mission. It will take us, collectively using our imagination, to achieve the outcomes we envision in these principles. And it will take us acting, together and individually. I would argue that the time has never been better for you to become engaged within the AAIDD. We have large initiatives underway, such as the SIS, for which there is much yet to be done. Individual members can use their positions within state governments to move toward the adoption of practices and policies that embrace these innovations; agency heads and direct support professionals can lead in using tools like the SIS to create individualized plans that design innovative supports. Students and researchers can begin to ask the

research questions and conduct the studies that refine these tools and evaluate their impact.

There are other initiatives underway within AAIDD, as well, in which members can serve a catalytic role: the development of a children's version of the SIS, the development of the Diagnostic Adaptive Behavior Scale under the leadership of Marc Tassé and members of that committee, and the AAIDD environmental health initiative. The latter provides even more opportunities for participation and involvement with webinars and trainings. If you are a healthcare professional and can contribute to the environmental health activities, the door is open.

Another critical issue in which you can become engaged involves the recruitment and mentoring of students and early career professionals. Only 32% of our members are below 50 years of age, and only 15% are younger than 40. Under the leadership of a strong and committed group of students and early career professionals, AAIDD has made progress in addressing these issues, as evidenced by the variety of activities conducted by the AAIDD Student and Early Career Professionals Committee in Providence. But, we can always do more and we must. And if you are among those students and early career professionals here, my charge to you is simple—get involved.

There are many other avenues for involvement. There is always a need for active leadership and participation within the association's regional structure and state chapters. We continue to support divisions, special interests groups, and action groups that target issues that are of interest to members, and as in regions and states, there is room for committed leaders and active participants. We have introduced a dynamic, powerful web presence to facilitate communication among members of these groups and to facilitate their efforts. And, if there is something that you are passionate about that is not represented here, that is what the action group process was designed to allow. Pull together a few others who are passionate about the same issue, form an action group, and do something!

Let me, in wrapping up, invoke another of President John F. Kennedy's legacies: the legacy of volunteer service. From the spirit of the Peace Corps, which he founded, to the memorable quote during his inauguration to "ask not what your country can do for you, ask what you can do for your country," Kennedy left a legacy of volunteerism. I will not insult you by paraphrasing the "ask

not" quote, I simply note that if you wait until someone asks you to help, you may miss your chance to be a part of establishing a new legacy. Trust me when I say that the plates of the officers and leaders are full. We make every effort to involve members and to engage members, but ultimately, it is you who has to act. Do not wait to be asked, reach out and volunteer.

Let me close by returning to the legacy of Dr. Burton Blatt. After the first edition of *Christmas in Purgatory* was published, Dr. Blatt received heavy criticism from other professionals in the field. His response was this:

In spite of those who protest this presentation, there will be no turning back; the truth can no longer be concealed. Some good must come from all this pain and anguish to so many institutionalized residents and their families. Once seeds are sown, one only has to wait for the crop to harvest. It has also been said that, when the bellman is dead, the wind will toll the bell. So hurry, wind! Or revive yourselves, noble bellringers. (Blatt, 1971, p. 15)

The tolling of the bell is the demand for inclusion, full citizenship, and self-determination. The wind—societal forces exerted by the voices and actions of people with disabilities—will, I am convinced, eventually toll the bells of inclusion and equal citizenship. But, it will toll sooner and louder if people with disabilities have allies among those of us who are professionals in the field. The question we must ask ourselves, fundamentally, is whether we are willing to be the noble bellringers needed to toll that bell. If your answer is yes, then I invite you to join the efforts of others within AAIDD committed to these outcomes. Let us leave a legacy that the president of AAIDD in 2076 will extoll on the advent of the association's 200th anniversary! Thank you for all you do for AAIDD and for the field.

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