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Creating Sustainable Reform: Aligning Our Generational Prisms

Valerie J. Bradley, President 2005–2006
American Association on Mental Retardation

It is never wise to assume that progress is a constant unless there is an abiding commitment to make it happen. The gains that we have made in the field of intellectual and developmental disabilities may seem robust and lasting, but history suggests that such hard-fought reforms can be lost in the face of complacency and self-satisfaction. I have been astonished over the past several years to see the progress that was made in the 60s and 70s—in such areas as the environment, worker health and safety, arms control, and civil rights—so quickly erode when the energy for change shifts to those determined to dismantle crucial policies.

The history of our field over the past half century has been nothing short of miraculous. Since World War II, we collectively focused a harsh light on the conditions in public institutions, we improved public policy to ensure the well-being of people with disabilities, we created a system of community supports from the ground up, we honed our assessment and planning tools to take into account each person's needs and aspirations, we elevated the status of individuals and families to policy councils, and we created laws that protect rights and individual dignity. Much of this incredible burst of progressive energy and accomplishment was fueled by the horrors that were revealed when the curtain was lifted on the dreadful conditions in public institutions around the country several decades ago.

The injustices behind the curtain were exposed by a phalanx of people who believed that housing people in subhuman circumstances was wrong and had to change. What followed was a spate of exposés, a wave of right to treatment litigation, changes in state and federal legislation, growth of the family advocacy movement, and the beginning of a decades' long movement of people into communities. Many members of AAMR were in the forefront of the reforms in the 60s and 70s, including Burton Blatt and Gunnar Dybwad. Many of us in AAMR were radicalized by the conditions that

we saw first hand as direct-support workers, clinicians, researchers, or advocates. Our experiences and successes forged a bond of friendship and collegial regard that continues to this day.

People in that generation were also influenced by a larger political culture that was shaped by opposition to the Viet Nam War, growing feminism, and the civil rights struggle. That generation, however, is moving inexorably toward retirement. As we look around at those in our organization, at the leadership in state agencies, in provider agencies, advocacy groups, and research institutions, we see a disproportionate number of people whose attachment to our field was shaped by events that took place decades ago.

I suppose the hubris of each generation is the assumption that succeeding generations will celebrate and carry on their accomplishments. This only happens up to a point and only if the trajectory of reform continues to be consistent with the assumptions and experiences of those left to carry on. Each generation must find its own truth and its own *raison d'être*.

It is safe to say that the future will not be like the past. The field that many of us grew up in is already barely recognizable. Budgets in some states range into the billions. Many former Mom and Pop agencies have been absorbed into increasingly larger and, in some instances, multi-state enterprises. Very few public institutions are left, although they are still being tenaciously defended where they do endure. The federal government through the Centers for Medicare and Medicaid Services is now an equal partner in the provision and oversight of services. The Internet has added new and more efficient ways to communicate and to analyze and transmit data. In some states, public agencies concerned with intellectual and other developmental disabilities are being merged with aging and other disability programs.

The important question is not necessarily the

shape of the future but the values that will guide the evolution. The tools that ensuing generations will use will not be the ones we use today, but they will, hopefully, be put to use in aid of the same cause. A spirit of vigilance is crucial to ensuring that the prospects for people with intellectual and other developmental disabilities and their families continue to grow and expand. Our challenge is to put in place mechanisms that will support these values and will distribute them into aspects of policy and practice that will be durable and resilient. There are a number of ways to proceed.

Tell Our Stories

Recently, I spoke with a colleague who works for a state developmental disabilities agency. I asked him how he got into the field, and he told me that he started as a direct-support worker in a state hospital many years ago. He then told me that he rarely talks about it because of the conditions there and the guilt he feels because he did not do more to improve things. I suggested that he was a young man then and that his experience, though difficult, continued to shape his work and his commitment to public service. I also suggested, however, that telling his story about those experiences was important because it reminded people of the deplorable conditions that our society tolerated only a few decades ago. For my own part, going through Pennhurst State Center in the early 1970s is imprinted on my psyche; I can still see the seemingly endless rows of cribs filled with people whose bodies were permanently contorted into painful contractures.

I bring up these examples because it is incumbent on all of us over 50 to keep this history alive and to embed it in the consciousness of people both inside and outside our field. Unlike Jung, I do not think that we can rely on a continuum of consciousness or unconsciousness to carry our values forward. We have to tell our stories to all who will listen.

Those of us in the older generation also need to get into the habit of listening to the stories of younger people. Their perspectives are shaped by different but equally valid experiences. They see possibilities and horizons that may not be visible to those of us forged in the 60s. I was always amazed by the way that Gunnar Dybwad continued to grasp and champion new ideas. Although part of that may have been his innate optimism and curiosity, it was also his continued contact and friendships

with succeeding generations of students and advocates that kept him looking over the next hill.

Mentor Others

Many of us came to this work under the tutelage and mentorship of valued colleagues and friends. My mentor was Arthur Bolton, a leader in the development of public policy in California, who was responsible for the foundation of the state's community developmental disabilities system, namely, the Lanterman Act. Art helped me, when I was a legislative staffer, to see the injustice inherent in the segregation of people with disabilities in remote custodial facilities and to explore the emerging research that showed that far from improving in institutions, people with disabilities were more likely to lose skills. In the end, people remained in facilities because of unexamined assumptions about the need for "asylum" and, more darkly, because of a suspicion that people with disabilities were sources of contagion and, therefore, not deserving of lives lived in our communities. Art's example and passion ignited my interest and ultimate commitment to this field, and I am sure that most of you can testify to the influence of a mentor on your career choices and on the way that you approach your calling.

Regardless of where we are in the field—provider, researcher, self-advocate, family member, or administrator—we have a responsibility to help those beginning to explore our work to understand not just the technical aspects of practice, but the underlying values and the history that have brought us here. Stressing the humanity of each person, the uniqueness of their gifts, the importance of individually tailored supports, and the importance of choice and self-determination is critical to ensure that those who will replace us bring both their skills and their hearts to the job.

Strengthen Collaboration

The next few years may be very difficult given the extent of budget deficits, continued tax cuts, and the pressures generated by ongoing war in the Middle East. In times like these, tensions among stakeholders are heightened. Advocates blame bureaucrats, bureaucrats lose patience with providers, and providers end up feeling buffeted by both. Although debate and strong advocacy are important for the health of our field, imputing bad motives

and demonizing the other side only serve to undermine our progress and provide openings for those who would erode our gains.

The strength of this field over the past several years has been the emergence of a consensus regarding our general course and the vehicles necessary to get us there. Allowing the strains of budget constraints, waiting lists, and deferred cost of living increases to magnify cracks in our solidarity will inevitably hobble our effectiveness. In *Civilization and Its Discontents*, Freud coined the phrase the “narcissism of minor differences” (1961, p. 72). Referring to earlier work by British anthropologist Ernest Crawley, Freud said that we reserve our most virulent emotions—aggression, hatred, envy—for those who resemble us the most.

This instinct is sometimes magnified in our world given that our passion can translate into righteousness, which in turn can breed a lack of tolerance for those who do not align precisely with our philosophical prescriptions. This manifests itself in invidious distinctions between those who “get it” and those who do not.

It is at times like these that we need to minimize our differences, philosophical and otherwise, to ensure that we do not provide openings for others to exploit.

Support Leadership

Our coalitions should increasingly involve people with disabilities, family members, direct support professionals, and others who have not traditionally been part of our deliberations. If we are true to the goal of reaching out to emerging leaders, we should also make a concerted effort to include people who were born after 1964, the last year of the Baby Boom.

To make these coalitions successful will require grooming new leadership. Although some of this will happen organically, we need to be more intentional given the generational disparities that currently characterize the leadership in the key institutions in our field. We need to create opportunities for leadership and leadership training at all levels. It also means being more inclusive in councils of power, whether it is a board of an agency, a state advisory board, a Developmental Disabilities Council or a faculty committee. Unless people have the experience of functioning in these settings, they will not be able to build the skills they will need. Once at the table, we also must be willing to open

ourselves to new ideas and fresh perspectives. People in my generation have been talking to one another for a very long time.

Reach Out for Increased Diversity

The leadership of key organizations in our field is still decidedly White. The AAMR, like the rest of the field, has not been very successful in attracting people from racial and ethnic minorities. By reviewing the changing demographics in this country, it should be obvious to everyone that we are increasingly living in an exceedingly diverse society. This diversity is reflected in the direct support professional workforce but, as yet, is not reflected in the upper echelons of the institutions in this field. The lack of diversity in these ranks means that we are deprived of perspectives we need to make sure that our research, advocacy, and services are responsive to a range of cultural norms.

Become Politically Involved

As I noted at the beginning of this paper, we are watching an extraordinary rollback of some of the key pillars of the American Welfare State and a conscious effort, as one tax conservative has called it, to “starve the beast” of big government by running up debts as far as the eye can see. As an organization, we are allied with our colleagues in the Arc, United Cerebral Palsy, ANCOR, and other national advocacy organizations to advance our policy aims and to fight the diminution of hard-won federal benefits and protections. This effort is mirrored at the state level.

Although our voice is strong and articulate, it is one of many and, in the current climate, is often drowned out by better funded and more numerous interests. If we are going to continue to be successful in ensuring the well-being of people with intellectual and other developmental disabilities, we all need to be participants in the political process. What does that mean? It means being informed on the issues and the stands that our elected officials at all levels are taking in our name. It means voting—and not just every 4 years but for everything from your local school board to city council to sheriff and judges. If we do not vote, you can be certain others will; and they will not necessarily share our priorities.

In the presidential election in 2004, only 64% of voting age adults went to the polls. Why? Be-

cause people do not believe that their vote will count, and they are not helped to understand the very real connection between their lives and what they care about, and what happens in the halls of power. If we want public policy to continue to reflect our best hopes, we cannot expect others to do it for us. The next several years will be critical. The decisions that will be made regarding economic and domestic policy will dictate the boundaries of our possibilities for decades to come.

Engage in Succession Planning

I suppose that much of what I have been discussing amounts to a conscious effort to do succession planning so that the “hand off” to the next generation is done in a thoughtful and strategic fashion. We owe it to those whom we support to nurture those who will come after us, regardless of what generation we are in. This is true whether you are a self-advocate, a case manager, a residential supervisory, a family member, a state commissioner, or an executive director. The future has a way of sneaking up on us. It is crucial to begin the process of renewal substantially before the day when the virtual gold watch arrives. Sustainability requires an unbroken chain of concern and competence. That will mean identifying people in our own organizations, encouraging them, and giving them the opportunities to develop their own reputations. Although not all transitions will be seamless, we can at least be sure that disjuncture and dislocation are minimized. Luckily there is still time. As Abraham Lincoln said, “The best thing about the future is that it comes one day at a time.”

Develop Tools to Guide Practice

The way that we can project the values that we care about into the foreseeable future is to develop useful tools for the field that embody and make manifest these values. The AAMR has been at the forefront of doing just that. The most recent contribution to valued practice is the Supports Intensity Scale (SIS), a tool for individualized planning based on the supports concept and stressing individual strengths as well as challenges. The SIS is a logical outgrowth of the Association’s definition of *mental retardation*, which has evolved to a construct that recognizes each person’s unique abilities and is premised on the notion that peoples’ abilities are in large measure a function of their environ-

ments and the availability of appropriate accommodations. There are other valuable planning tools that carry forward our aspirations into practice, including Michael Smull’s Essential Lifestyle Planning and Beth Mount’s Personal Futures Planning.

Another important means of building values into practice is to develop direct support curricula that teach staff members the importance of individual respect, choice, and empowerment and that give them the skills to support people to maximize their participation in their own lives and the lives of their communities. The College of Direct Support is one great example of building values into training for people who *provide* support and care. There are now a number of states that have developed voluntary credentialing for direct support professionals; these programs include the mastery of competencies based on person-centered practice.

Solidify Policy and Regulation

Although improving federal policy on behalf of people with disabilities may be a tough go for the next several years, many opportunities are available at the state level to embed values and person-driven practices. One way is to embed such outcomes into our quality assurance systems. This is done by rewriting licensing and monitoring protocols to reflect the preconditions for individual choice to describe the components of consumer-driven planning, and to require inclusion of people with disabilities and families in governing bodies. Quality standards should not be just a series of decades old requirements, the rationale for which has long been forgotten. They should be dynamic documents that contain our best hopes for the provision of services and supports. Quality standards and indicators should also result in the propagation of data that allow people to gauge whether the system is living up to its aspirations.

There are also other policies that, if modified, can provide vehicles to a sustainable future. There are many opportunities to establish our values and our vision in operational mandates. Targets of opportunity include rules governing case management that stress individualized planning, rate setting that is based on the need for supports and that can be translated into individual budgets, monitoring that includes people with disabilities and families, and broadly constituted quality councils that participate in the enhancement of services based on performance information.

Celebrate Our Successes

We are all privileged to be part of one of the most impressive social reform successes in recent history. The prospects of children born today with disabilities and the parents that bring them into the world far outpace those of earlier generations. The segregation of people with disabilities in public and private institutions, although still a reality, is rapidly diminishing. The life expectancy of people with intellectual and other developmental disabilities has expanded beyond what we could have imagined when I first came into this field. The human and civil rights of people have been acknowledged and protected at the federal and state level. Finally, and perhaps most important, many of us count people with disabilities as close friends and allies.

These are difficult times politically, socially, and economically. It is important for our sense of progress and to maintain our momentum that we hold on to those successes and remember to acknowledge and celebrate them.

Face the Challenges of the Future

Taking pride in our accomplishments does not mean that we shrink from recognizing the many difficult shoals still to be navigated. There is still much work to do. Although these tasks may not result in the revolutionary changes that propelled us from the dark days of the eugenics movement to today, they are equally taxing in terms of the energy and attention that will be required. In many ways, our job will be more difficult because it entails the arduous work of building a robust infrastructure. At the top of the list is finding ways to ensure that we have a stable and competent workforce, which will require securing a living wage, creating career paths, and providing relevant and accessible training. We

also will need to create an environment in which people with intellectual and developmental disabilities are masters of their destinies and make choices that are critical to the achievement of their own aspirations. This will necessitate substantial changes in our assumptions about who is in charge as well as how we fund services and the quality assurance approaches we need to support self-directed services.

In closing, I want to summarize an earlier statement and stress that the major challenge will be continuing to attract young people to this field that we all care so deeply about, to maintain continuous leadership and innovation, and to carry forward an understanding of the injustices that propelled us to this point.

James Baldwin, in *Nothing Personal*, which was published in 1998, captured the responsibility that each generation has to the next in the following words, which speak *to* me and speak *for* me:

For nothing is fixed, forever and forever and forever, it is not fixed; the earth is always shifting, the light is always changing, the sea does not cease to grind down rock. Generations do not cease to be born, and we are responsible to them because we are the only witnesses they have. The sea rises, the light fails, lovers cling to each other, and children cling to us. The moment we cease to hold each other, the sea engulfs us and the light goes out. (p. 706)

References

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Author:

Valerie J. Bradley, MA, Human Services Research Institute, 2336 Massachusetts Ave., Cambridge, MA 02140. E-mail: vbradley@hsri.org