

Perspectives

President's Address 2008 Creating the Future: Beyond Our Inheritance of the Past

David A. Rotholz, President, 2007–2008

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In some organizations, people seek the presidency as the culmination of a career, as feather in their professional cap, or perhaps because they think they are the absolute best person to hold the position. Still others may seek the presidential role because they want to “be the association president” or relish the opportunity to make a presidential address. Fortunately, the American Association on Intellectual and Developmental Disabilities (AAIDD) has had many presidents who sought the position because they believed they could make a positive difference for the association and the field of intellectual and developmental disabilities.

I am in the latter group. I am not a full-time researcher, although I am fortunate to contribute to the applied research literature. I am not currently a service provider; however, I am directly involved in improvements to a service delivery system that has an impact on the lives of people with intellectual disability. It is not exactly like being a round peg in a square hole, but it is difficult to adequately describe what I do in a job title or a single sentence. What is clear, however, is that I am extremely fortunate to have a career focused on issues and solutions that are important in the lives of people with intellectual and developmental disabilities and to have a professional life that I find intellectually challenging, socially relevant, and personally satisfying. It has been an honor to serve as AAIDD president and to work with the talented individuals who serve as our executive director, officers, and members of the Board of Directors; our national office staff; and other highly active members. I hope that we have made valuable contributions.

The achievements of AAIDD to this point constitute the foundation of our current association. The hard work, visionary undertakings, and tenacious accomplishments—they are what past leaders and members have contributed. It could be

viewed as the inheritance that we provide to the future.

This description may resonate with some of you, and some may think it is a bit melodramatic. I think it is particularly appropriate given the transition across generations that has recently begun. The retirements by leaders in the field of intellectual and developmental disabilities will bring change. Those leaders who came of professional age as the nation awakened to the rights and needs of people with intellectual disabilities in the 1960s are in the twilight of their careers. Doreen Croser, the talented person who has led AAIDD for the past 20 years as executive director, intends to retire in the next couple of years. Her vision, skills in management and collaboration, tenacity, and expertise directed toward the success of AAIDD will be a tough act to follow.

We know the inheritance we are passing along to the next generation, but what future will we create with this rich legacy?

We are fortunate for the efforts to address the looming shortage of intellectual disability professionals. Steve Eidelman and others working with the National Leadership Consortium on Developmental Disabilities at the University of Delaware are prime examples of such an effort. Let's hope their work will contribute to the next generation of leaders.

My focus today is not on we have already done. It is what we still need to do. It is about how we build upon our inheritance. It is about the future. The “we” is not AAIDD as an organization, although we certainly have an important leadership role to play. This includes the AAIDD officers, Board members, and regional and state leaders; yet, the leadership and national office staff cannot do this alone. The future success of AAIDD relies on action by its individual members: action by you.

*The future is not some place we are going,
but one we are creating.*

—John Schaar

I have four venues to which you might choose to direct some of your energies. None of the four will surprise you. This address at its very core centers on values.

When thinking about the supports for people with intellectual disability a key question is what is required if one is to live a meaningful and fulfilling life? When someone asked Sigmund Freud what was necessary for a happy life, he said simply “to love and to work.” You may be surprised that a board-certified behavior analyst would quote a psychoanalyst, particularly Freud. My view is that if it’s the truth, it doesn’t matter who said it.

Having a life that meets our personal definition of *high quality*, being treated with dignity and respect, and having meaningful activities in which to spend time are goals that would resonate with most people. Fulfilling our professional roles to help increase the likelihood of these outcomes for people with intellectual disability is part of the future for which AAIDD strives. This is why the areas I will focus on in this address include (a) living in the community, (b) meaningful work, (c) practices to support appropriate behavior (which often make the first two possible), and (d) examining quality. As professionals, we would probably all agree on the centrality and importance of these areas.

Living Good Lives in Communities of Choice

Where and with whom one lives are fundamental components in a personally satisfying life. We all have our individual preferences; that is human nature. Being able to choose our living arrangements is how we help to ensure that our preferences are met. The progress over the past 40 years in supporting people with intellectual disability to live in a community of their choice is remarkable. However, a tremendous amount still needs to be done.

The number of people living in institutions is down significantly from the “bad old days” when people with intellectual disability were warehoused in abominable conditions. Charlie Lakin and his colleagues at the University of Minnesota (Prouty, Smith, & Lakin, 2007) and David Braddock and his colleagues in Colorado and Illinois (2008) keep us regularly informed on our progress and areas of need. We can look with pride to see how many fewer people live in large institutional settings. We can be glad that the trend of decreasing numbers of people living in these settings continues. However the trend has slowed. Approximately 38,000 people still live in large state facilities in the United States.

A key challenge in the future we are creating is to make available more community support opportunities. It is not enough to say we want less people to live in institutional settings; we have to take the actions to see that more community supports are available.

A recent study conducted by the Human Services Research Institute and the Research and Training Center on Community Living at the University of Minnesota (Lakin, Doljanac, Byun, Stancliffe, Taub, & Chiri, 2006) compared outcomes of home and community based waiver and intermediate care facility (ICF/MR) supports across six states. Most notable about the 3,000-person data set was that it used the National Core Indicators consumer survey as a key data collection instrument—in other words, a validated instrument for assessing consumer satisfaction.

It was not surprising that the data showed that people living in the community with home and community based services and supports had much greater levels of choice in daily life. It was also not surprising that more negative findings in the area of well being and satisfaction were always associated with larger residence size.

Another recent study by Stancliffe et al. (2007) included many of the same authors and

There is no passion to be found playing small—in settling for a life that is less than the one you are capable of living.

—Nelson Mandela

conducted a similar, multistate analysis of data collected as part of the National Core Indicators program. This study examined the issues of loneliness and living arrangements. The finding that was most applicable to the issue of where one lives was that “more loneliness was reported by residents of larger community settings” and that “loneliness was not more common for people living alone or in very small settings” (p. 380).

The authors of the six-state study recommended that we need to expand Medicaid waiver supports to accommodate people in community settings regardless of the level and nature of their disabilities. Thus we need to dramatically increase our efforts to help people in large ICFs/MR to move to community settings. One poignant recommendation is to avoid the need for deinstitutionalization in the future by ensuring that people are not placed in large facilities in the first place.

Some important questions are: What is the current status in your state? Is this an issue important to you? And, if so, are you directly involved in the solution?

Another issue of critical importance related to community supports is not just whether the person moves to a community location but whether this is a home that they choose to live in with people they choose to live with (if any). Although this will not guarantee that the person is actually integrated into their community, the data thus far show that a home in the community is likely to lead to a better life.

In a recent report on residential services for persons with developmental disabilities, Prouty, Smith, and Lakin (2007) reported that, nationally, 24.6% of people who receive residential services live in their own home.

To be honest, these numbers are higher than I had expected but lower than they should be. Nonetheless, I found them surprising. Perhaps that is because my state of South Carolina is reported to have 13% of people receiving supports living in

homes of their own. This compares with a range across states that goes from a low of 1% in Delaware to a high of 80% in Nevada.

Last year, I invited a plenary address on community living by Derrick Dufresne and Bob Laux. I truly appreciated that session because it described not only how nontraditional funds (i.e., low-income housing and/or supplemental security income [SSI]) can be used to rent or purchase a home of one’s own, but also because it demonstrated how individuals with intellectual disability can find homes of their own, if not home ownership, in a community of their choice.

Others have written about similar efforts. We have a relatively small project at my center in South Carolina that conducts this work in collaboration with the state developmental disability agency, the local public housing authority, and other community resources. Seeing people live in places of their choice helps “put a face” on the project. It is a reminder that although policies and studies play an important role in these efforts, they do not make it happen. Individuals working diligently for a dedicated purpose do.

We have a current situation in which, at best, three quarters of people with intellectual disability who receive services do not live in a home of their own. Clearly, we can do better. Just as we helped create meaningful change in deinstitutionalization—helping to move well over 100,000 people out of large state facilities—we can create meaningful change to see that many more people have real choices when it comes to where they live and with whom.

Meaningful Work

I quoted Freud earlier on the importance of work to a happy life. Why is it that work is so central to happiness? How we spend our workday may not define us, but it certainly has a major

influence on our personal satisfaction and how we are viewed in our community. Whether our vocational pursuits are paid or voluntary, full or part time, independent or with supports, what matters most is that the choice is ours and the result is personally satisfying.

National data on supported employment show a disturbing trend (Braddock et al., 2008). Braddock et al. noted that “in 2006, the proportion of supported employment workers in all day and work programs had dropped to 21.5%. This was the lowest level in eight years, and below the peak of 24% in 2001” (p. 40). Fifty-six percent of all people who received day-work supports received those services in segregated settings.

We have known for a long time that sheltered workshops are not what we would call an appropriate work outcome. In many cases, what occurs in sheltered workshops is not work at all, but a place to send people because it is convenient.

I, like many of you, have spent time observing, working, and/or visiting in sheltered workshops and real work settings in which people with intellectual disability are supported. Across sheltered and integrated work settings, the differences are obvious. In many cases, the sheltered workshops are a sad reminder that the functional versus nonfunctional activities contrast is *not* a thing of the past. Unfortunately, it lives on in many sheltered workshop settings, along with the segregated historical remnants of a feeble vocational effort.

In all fairness, I have seen a sheltered workshop or two that had comparatively well-paying contracts though which the employees with disabilities earned decent money and the work was plentiful. A new Walgreens distribution center in my state is part of a major corporate effort creating real jobs, in an integrated setting, with the intent to have one third of the workforce composed of people with intellectual disability. Unfortunately, this is a notable exception. In many cases, the sheltered workshops look like throwbacks to the old institutional days—rooms in which the goal is to have people basically pass time with a minimum of problems, settings in which people are congregated because they have a disability, days in which little productive time is spent and with no meaningful outcomes, time wasted.

In the mid-1980s, I was the clinical director of a community based educational and residential treatment program in Massachusetts for people with intellectual disability, especially autism. I recall

clearly the struggle we had changing our program to include only functional activities and materials. This was about a decade after Lou Brown (Brown, Nietupski, & Hamre-Nietupski, 1976) and colleagues had called for functional activities in school settings. Never in my worst dreams did I think that more than 20 years later we would still be fighting to ensure that the services and supports provided for adults with intellectual disability have application to meaningful employment. It is appalling that we can still find coloring books and other such materials in some workshop settings for adults.

In 2001, the U.S. Department of Education amended their regulations governing the Vocational Rehabilitation Services Program, for good reason. They no longer included placement in segregated settings such as sheltered workshops as an appropriate employment outcome. Instead they defined an appropriate employment outcome as full- or part-time employment in the integrated labor market.

In 2005, the state of Vermont closed its last sheltered workshop, completing a gradual process that had begun 6 years earlier (Sulewski, 2007). They accomplished this through collaboration with the state vocational rehabilitation agency, the University of Vermont, and local provider agencies, taking care to ensure that existing workshops were converted to individualized supports before the policy change that eliminated funding for the workshops.

The state of Washington’s Division of Developmental Disabilities has also recently enacted a policy that “designates employment supports as the primary method of furnishing state-financed day services to adult participants” (Policy 4.11, April, 2008). Although the policy has not eliminated sheltered employment, it has refocused support efforts and is already providing measurable gains.

Thus, there is room for optimism. I would also note that there is a recent effort by the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston and the National Association of State Directors of Developmental Disability Services (NASDDDS) called the State Employment Leadership Network. The collaborative effort is committed to assisting states to improve employment outcomes for the people they serve. The network currently has 16 participating states plus the involvement of NASDDDS and the ICI in Boston.

The accomplishments in Vermont that closed all workshops, in Washington that produced

Let me tell you the secret that has led me to my goal. My strength lies solely in my tenacity.

—Louis Pasteur

measurable improvement, and the new State Employment Leadership Network are examples of people taking action. Let's learn from the Vermont and Washington examples and keep current on activities of the employment network to see what strategies they find most effective, what obstacles they navigate around, and, most important, what we can do to become involved in resolving the lack of meaningful employment outcomes.

A personal example is relevant here. Recently, I stopped at a fast-food restaurant on my way to work. I was pleasantly surprised to see that the one person taking orders was a woman I know. She has been a paid consultant to our center on multiple projects including my own. She found a home of her choice though our community development project. She is an advocate who has received support from the University Center for Excellence in Developmental Disabilities where I work.

I bring this up because I know how long Tammy had to wait to get that job and how many obstacles had to be overcome. This is not a job at a nuclear facility or Division of Homeland Security. It is a cashier job at a fast food restaurant.

The problem was not on the part of the employer. The problem was that she receives services that are mired in bureaucracy. It's like the old saying that no one ever wants to hear, "We are from the state and we are here to help you."

The employer was willing and helpful. The vocational agency, however, ran into multiple internal obstacles in accomplishing their task. Although they were willing partners, they needed assistance to help Tammy get her job. Fortunately, a staff member at our center, in collaboration with the state disability agency, spent the hours, days, and, unfortunately, months following through with the details that needed to be addressed.

I bring this up because Tammy is happy with her job and proud that she has it. However, thinking about what she had to endure to get her

job makes me realize how wrong the process was. It is disturbing, it is sad, and, unfortunately, it is not unusual. Her patience and persistence in seeing the process through to a successful outcome are admirable. However, it should not be necessary. Her example is one of the faces behind the fact that the percentage of individuals with intellectual disabilities in supported employment is lower than it has been and lower than it should be. We can do better and we will do better only if we make it happen.

Positive Behavior Support

Positive behavior support (PBS) is a "set of research-based strategies used to increase quality of life and decrease problem behavior by teaching new skills and making changes in a person's environment" (Association for Positive Behavior Support, 2008, www.apbs.org/new_apbs/genintro.aspx). PBS has been described as the "evolution of a science" (Carr et al., 2002, p. 4) that has emerged primarily from applied behavior analysis, the normalization-inclusion movement, and person-centered values (Rotholz & Ford, 2003). The use of PBS, as contrasted with strategies focused solely on behavior reduction, reflects the implementation of our person-centered values within an evidence-based paradigm.

The area of behavior has been a focus of AAIDD's for many years. This has been reflected in our policies and position statements. Publications in this area historically have been bestsellers for AAIDD because of the unmet need to replace a deficit model with a positive skill-building model.

The professional literature on the need for positive approaches to supporting appropriate behavior goes back decades (Carr et al., 1999). The article by Horner et al. (1990) on positive behavioral support, titled "Toward a Technology of

Opportunity is missed by most people because it is dressed in overalls and looks like work.

—Thomas Edison

‘Nonaversive’ Behavioral Support,” and the several reactions to it appeared in what was then called the *Journal of the Association for Persons With Severe Handicaps* 18 years ago. Earlier, works going back to the 1970s both demonstrated the effectiveness of skill building and nonaversive approaches and contributed to efforts to require deinstitutionalization (as described in Thompson, 1990).

We might be forgiven if we thought that 20 years would be sufficient time to accomplish changes in behavioral practices that are supported from both ethical and technological arguments (Carr et al., 1999; Horner et al., 1990). However, research does not necessarily result in policy and policy does not ensure action. So, why then are there continuing examples of routine coercive behavioral practices used with people who have intellectual or developmental disability? Why are there so few examples of widespread use of positive behavioral supports in settings for adults with intellectual disability?

A few years ago a colleague and I described implementation of a statewide system change in positive behavior support (Rotholz & Ford, 2003). We detailed how a series of coordinated and interrelated efforts are needed to affect change in PBS statewide. Some of you know that this project is the source of the AAIDD *Positive Behavior Support Training Curriculum* (2007), a bestselling publication for AAIDD and a curriculum that has been continuously used in one state for the past 10 years.

My reason for bringing up our effort in South Carolina is that although we have made significant gains, we are not yet where we want and need to be. Positive behavioral supports are not universally implemented, and vigilance to make the needed gains remains a challenge. The primary goals, on which we must remain focused, are that people with intellectual disability have the opportunity for meaningful lifestyle change and that people who display problem behavior receive the skills training

and environmental improvements that contribute to this outcome.

We are continually reminded that there are many factors that are necessary but not sufficient to produce meaningful change toward positive behavioral supports. These include philosophical, political, and financial support from the agency leadership; competency-based training for supervisors, trainers, direct-support professionals, and behavior support plan developers; an effective process to ensure that behavior support plans are developed by people with appropriate qualifications and that they do this with the input and collaboration of those involved in providing and receiving the supports; and a quality assurance–quality improvement process specifically focused on PBS.

No single factor is responsible for meaningful improvements. In some cases, positive change has been the result of an executive director’s actions made possible from an increased understanding of the key issues. In other cases, community home supervisors or case managers have demanded professional best practices by behavioral consultants. Yet other cases have come from some talented professionals in applied behavior analysis and PBS who work with local agency staff to create a paradigm change to PBS.

The reality is that it takes action by people to produce meaningful change. Policies are important but not sufficient. Some of us work to create system improvements that directly affect people’s lives. Such a system includes tools that educate, evaluate, and, yes, require necessary change. We cannot rely on “the system” or “the agency” to get this done. We have to be active participants, willing to push the envelope in a way that includes the technical assistance to make change possible. It is not quick, it is not easy, and it is not always enjoyable. However, with our focus on what matters most, on enabling meaningful lifestyle change, and on

working with the organizations responsible for the supports and services, we can make it happen.

Quality of Life

Quality of life is difficult to define (Community for All Toolkit, 2004). As individuals, we each have our own preferences and, thus, our own definition. However, based on the framework that O'Brien and Lyle O'Brien (1987) provided, we can view quality of life as the valued experiences of sharing ordinary places and activities; making choices; developing abilities and sharing personal gifts; being respected and having a valued social role; and growing in relationships.

Not surprisingly, quality of life permeates every issue in this address. It is also no surprise that many AAIDD leaders are national and international leaders in this area. Past-Presidents Valerie Bradley and Robert Schalock work extensively in areas related to quality of life and have a recent book on the topic, along with Jim Gardner, AAIDD's current secretary/treasurer (Schalock, Gardner, & Bradley, 2007). In fact, most Board members spend their day jobs focused on this issue, and many of us are involved directly in issues related to quality, whether it is the services and supports, the models for conceptualizing it, research that studies it, assessments to identify needs related to it, outcomes that lead to it, evaluations of it, or policies that affect it. The most basic issue regarding quality of life is that we all deserve an equal chance for the quality of life that matters most to us as individuals. This is the moral imperative of our work, and this work requires moral courage.

For those who need supports from others, beyond simple rhetoric, the process gets more involved and more complicated. Historically, our field has not performed as well as it should have in providing supports of a quality that we would want for ourselves. Most of us can think back to examples that we either personally witnessed or, for some of our younger members, read about, that included levels of quality that we would choose to forget: situations to which no one should be subjected.

Currently, it would be rare for an organization that provides supports to people with intellectual disability not to say that they focus on high-quality supports. This would include organizations that range from a microboard that serves a few people to a state agency that serves thousands. Mission

statements regularly communicate the desire to provide the highest quality supports and services. Does the rhetoric reflect the reality in the lives of people within our sphere of influence and responsibility? Do we really know? The questions are: How are we doing now? Have we come far enough? Do we have confidence in the information about quality and the appropriate use of that information to improve services and supports?

With the increasing provision of services in community settings, the means of quality assessment have changed. One of the most encouraging aspects of how quality currently is viewed and assessed is the inclusion of consumer satisfaction measures. Personal satisfaction is appropriately viewed as integral to any assessment of quality.

The National Core Indicators and the Personal Outcome Measures both are prime examples of progress in how we look at quality today. The widespread use of these methods is a clear indication that we have come a long way from the point where there was a sole reliance on compliance standards to evaluate quality. With the National Core Indicators, we also have an interstate collaboration that provides a validated means to gather needed information on systems issues and personal satisfaction in key areas integral to quality of life. This 10-year collaborative effort among 28 states is led by the NASDDDS and the Human Services Research Institute (HSRI), as recently described by Bradley and Moseley (2007). The National Core Indicators is becoming an increasingly valuable tool for performance measurement in key areas of outcomes and satisfaction both within and across states. National Core Indicators data are increasingly being used by researchers to reveal important insights into the lives and perspectives of individuals with intellectual disability and families who receive publicly financed supports. The data also provide key information to guide strategic planning and policy at state and federal levels. The potential to "increase the quality and responsiveness of services and supports" (Bradley & Moseley, 2007, p. 357) is particularly encouraging given the impact that this can have on the lives of people with intellectual disability.

Those who allocate the federal funding for community services (i.e., Centers for Medicare and Medicaid Services [CMS]) have provided an impetus for modernized quality and performance management systems. The CMS Quality Framework is another example of how federal guidance

You must be the change you want to see in the world.

—Mahatma Gandhi

on quality assurance has changed. In addition, when the federal agency that provides the funding for the Home and Community Based Waiver Services speaks, state intellectual and developmental disability agencies listen.

There are good reasons to be encouraged about advances in the area of quality. We have a well-developed approach to conceptualizing quality of life thanks to Robert Schalock and others, personal outcome measures from the Council on Quality and Leadership in Developmental Disabilities, and methods to assess organizational performance with the National Core Indicators. However, even with these significant advances, important issues remain. Two key issues are the validity of the information gathered and how the data are used.

Collection, comparison, and evaluation of system performance data such as those collected with the National Core Indicators represent important progress. As previously mentioned, the National Core Indicators process is a validated one when used as intended. We need to be cautious, however, that whatever process is used to assess quality is properly implemented.

Currently, 27 states are experiencing budget deficits. During such periods of financial retrenchment, states frequently look to achieve cost savings by contracting out services previously provided by state personnel. In this context, some states may decide that the use of quality improvement organizations offers advantages. Although an external, independent process does bring some advantages, we cannot assume that simply because a process is external that it is valid.

My colleagues and I recently completed an independent evaluation of a state quality assurance–quality improvement system (Rotholz et al., 2008). The findings underscored the importance of maintaining a continuous focus on quality improvement functions, even when key activities are contracted out to entities such as quality improvement organizations.

State quality assurance–quality improvement systems must regularly evaluate the validity of the information they collect regardless of whether they contract with other groups to perform the assessments and compile the data. With policy decisions based on this information, the importance of its validity cannot be overstated. Whether the quality assurance–quality improvement system is conducted internally by the state agency or contracted to a quality improvement organization, a competent review of the process is needed to help ensure that the results are valid and can be relied on over time. An example of this would be the consumer survey that is part of the National Core Indicators process. This process, as with any other validated assessment, is useful only when implemented as designed. Checks and balances must be in place to ensure this or the results may be of questionable validity. Fortunately, in the study just mentioned, the state took the initiative to perform a comprehensive evaluation of its own quality assurance–quality improvement system. The result was part of a *discovery process*, to use the terminology of the CMS Quality Framework, and steps have been taken to implement remedial action. How often is the validity of your quality assurance–quality improvement process evaluated?

Evaluation and comparison of performance data reflective of quality are important first steps. However a well-functioning “feedback loop” is essential for continuous quality improvement. This should regularly assess quality of supports and the satisfaction of the person receiving the support and include the process steps to facilitate use of the quality assurance information to make short-term and long-term improvements. The focus must remain on what is most important, namely, that people with intellectual disability experience a quality of life that is personally satisfying. Our supports and services must maintain this focus. Processes and paperwork in quality assurance–quality improvement system should enhance this

effort, not substitute for it. Assuring and improving quality are ongoing processes that require vigilance at all levels. The question for those of you involved in promoting or assessing quality is are you confident in the validity of your process, outcomes, and data?

Conclusion

The key issues I have discussed have obvious importance in the lives of all people, including those with intellectual or developmental disability. Many of you are helping to create the change needed in one or more of the areas I have discussed today. Thank you for your hard work. For you, my request is to bring more colleagues, early career professionals, and students into the process. The demand is greater than our numbers, and we are getting older. For those of you not actively involved, I ask that you choose the area in which to contribute your professional talent. As AAIDD members and supporters, we all have additional ways in which we can help make a difference. Our efforts will shape the future of our field and our association.

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