

Presidential Address, 2015—Making a Difference Through Research, Practice, and Policy

Susan B. Palmer, President, 2015-2016

Introduction and Background

It is with great pleasure that I address my fellow members of the American Association on Intellectual and Developmental Disabilities (AAIDD). This audience contains mentors, colleagues, existing and emerging leaders at your agencies and universities, self-advocates, and the future leaders of AAIDD. As is often the case when one is asked to give remarks, the immediate thought is: What can I say that is meaningful and helpful to others? So, I'll begin at the beginning and give some insight into my leadership path. One question students often ask me at the University of Kansas is: How did your career in disability research begin? My career within this field began in general education. I earned a degree in elementary education at the Pennsylvania State University and received teacher certification right around the time that landmark legislation was signed in 1975 providing support for instruction and inclusion of individuals with disabilities in public schools. As special education in the public schools began and evolved into the system of services we have today, I raised a family of three children while taking disability-related classes in reading disorders and cognitive disabilities at universities in New York and Texas.

As current special education began with the Education for All Handicapped Children Act, enacted in 1975, and most recently evolved through the Individuals With Disabilities Education Act (IDEA, 2004), so did my perspectives on disability-related services. I also met Michael Wehmeyer, a fellow doctoral student at the University of Texas at Dallas, who is a beacon in the field of disability and self-determination and a mentor to many, including me and our colleague, Karrie Shogren, regarding research and effective practice. Mike also introduced me to AAIDD as a professional home. Following my work in early intervention—birth to age 3 services in family homes and a few years as a researcher at The Arc of

the United States—I settled into the role of research professor at the University of Kansas in Lawrence, working primarily to address the gaps in research for individuals with disabilities.

Another milestone in policy legislation that spans many of our careers is this year's 25th anniversary of the Americans With Disability Act (ADA), signed in 1990 by President George H. W. Bush. This momentous anniversary of the original legislation will also help me center my remarks on what has happened in the years since 1990, both within our organization and in the field of disability research, policy, and practice.

The Conference Theme

The 2015 AAIDD conference theme, *Making a Difference Through Research, Practice, and Policy*, was well illustrated through the conference's first two plenary sessions. Steve Warren talked about *research*; Robin Jones told us about the *policy* and *practice* outcomes of the 1990 ADA legislation for people with intellectual and developmental disabilities (IDD); and Michael Wehmeyer outlined how *practice* in the disability field has evolved in recent years through a focus on strengths rather than emphasizing needs, although, in some ways, we are still operating much like the 1980s in terms of disability supports. During the second plenary meeting, we heard about some of the next big ideas within employment from William Kiernan, community living from Amy Hewitt, education from Susan Copeland, and health care from David O'Hara. We want to thank all the speakers who brought their energy, ideas, and expertise to this 139th meeting of AAIDD. Our strength is in our varied, but focused, points of view, with perspectives aimed toward support for people with IDD.

Research and Practice

The definition of *research* involves an active search. So, when we talk about research, it's essentially a study of a subject, field, or problem,

undertaken to discover facts or principles. Another aspect of our conference theme, *practice*, is something we do, what we perform, and how we manage actions. The word “practice” in the context of my remarks concerns the activities and best practices that we use in schools, agencies, homes, and the community to support individuals with IDD. Practice depicts how we interact on a daily basis to bring about positive outcomes in the lives of people with IDD.

Our field has benefitted from the work of the National Implementation Research Network (NIRN), at Frank Porter Graham, University of North Carolina, Chapel Hill on effective implementation within practice. Founded by Dean Fixsen and Karen Blasé, this center conducts research on implementation of practices in real-world situations and continues to provide guidance and support for knowledge transfer and taking research-based practices to scale, in settings where other things are happening and ongoing daily activities continue to occur. The idea of taking a program to scale has been part of the U.S. Institute of Education Sciences (IES) research program for the last several years, in that one can work on a Goal Two Development grant, create an intervention that is feasible and socially valid, and gather initial proof that the work is effective. Then, if funded to pursue a Goal Three grant cycle, one can take the intervention to scale to prove the intervention is robust enough to be carried out in varied places and with individuals who need and will benefit from such supports and intervention.

Fidelity of implementation is extremely important, especially when one must turn over implementation to a number of other people who may not be as well-trained or as informed as the originators of the intervention. For example, Salyers, Becker, Drake, Torrey, and Wyzik (2004) reported a study of supported employment that yielded differential intervention effects for groups of individuals with disabilities. When results were grouped by low and high fidelity of implementation (the degree to which the interveners carried out the program as designed), only 40% of adults were employed in the low-fidelity cluster, as opposed to over 90% of adults within high-fidelity implementation sites. According to the authors, who were affiliated with the National Implementation Research Center, the programs were identical in nature except for the degree of fidelity of implementation of the training and intervention

plan. How one implements a structured program or service is important—fidelity of implementation makes a difference.

Research and practice often intersect. When innovative practices are identified, developed, and piloted, researchers look for ways to share information, strategies, and best practice. People involved in delivering best practice often consult with researchers to determine how to measure outcomes of practice. Another thing to consider regarding practice is the term “evidence-based practice,” which involves a body of scientific knowledge about treatments, prevention, intervention approaches, services, and practices; is research-based, structured, and manualized; and is tested via randomized trials with experimental and control conditions used to establish causation and access magnitude of effects. Socially significant outcomes are attained by using effective innovations, implemented effectively in enabling contexts (NIRN, n.d.).

As researchers, we see value in conducting studies in applied settings so we can translate research into practice. We can also work to build unselfish collaboration and partnership between groups of researchers, as well as to employ multidisciplinary perspectives, such as education, social work, psychology, philosophy, and medical communities, to generate important ideas for applied research. Not only are research partners important, but we must pay attention to the context in which we work. One other mission of established researchers should be to mentor young researchers and support staff during the research process.

As we consider practice, when does an intervention bridge the gap between efficacy and effectiveness? An efficacious intervention yields outcomes under ideal conditions, with high fidelity, using well-trained staff (Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001). In contrast, an effective intervention yields socially valid outcomes within typical conditions—even when the researchers are not monitoring training and implementation (Shoenwald & Hoagwood, 2001). So, as a researcher, the best outcome for effective work is to be able to take the intervention to scale in multiple locations under normal conditions of everyday activities within appropriate contexts that adopt the activities into typical practice.

I’ve spent a number of years in the recent past working with my colleagues in early childhood to

promote fully inclusive services for young children with disabilities in preschool classrooms, emphasizing access to the same general education curriculum and activities that other children experience. You may say, well, that's easy—the children are young, teachers won't mind, things are pretty available, and people can learn how to do this. However, that was certainly not the case. In fact, our team of early educators spent considerable time working through conflicting and confusing issues that often vex the best of us to come up with the ultimate framework involving choice for teachers in how to implement a curriculum framework that provides planning via Universal Design for Learning and the availability and ability to use challenging curriculum content, such as mathematics, science, literacy, and social skills, integrated into a coherent and comprehensive curriculum model. Getting teachers to agree that children with disabilities can be part of such an endeavor was another barrier. Some teachers agreed it could be accomplished, others were willing to try but were skeptical of it working, and still others refused to pursue the idea to completion.

In my experience as a research partner in schools and other settings, when someone mentions that they don't have time—that the paperwork demands are too high or that we need more training (to do something that is more akin to a change in attitude) or that they are not permitted to do it by a supervisor, who we have contacted in advance and is in agreement—we realize that this will be an uphill battle to accomplish very little. In your workplaces, what sorts of attitudinal changes are involved when you bring in new, refreshing ideas and the same sort of barriers are raised? In order to move forward, we need to make our case for change and work with those who are willing to show others that it is possible.

Policy

Policy is a set of basic principles and associated guidelines—guidelines that we have been involved with at AAIDD for some time and will continue to be involved in as the years pass. In order to discuss policy, I asked my friend, former colleague at the Beach Center and past president of AAIDD, Rud Turnbull, to provide his view on policy:

I regard policy as having three values. The first is that it reflects our beliefs about how we

should deal with people with intellectual disability. It doesn't always reflect them properly, but it does reflect them and, therefore, gives us a basis for change. Second, [policy] shapes our actions, it shapes our beliefs, and in that respect it tells us what we should do and what we should not do. In other words, policy is absolutely foundational to what we do and who we are. It is, I think, accompanied by two other foundations. One is the ethics of our profession, the ethics of indeed our country, and, second, the public administration of our work—that's to say, how we do our work. So I would encourage you to think in three dimensions about this matter of public policy. The first, as a reflection and a beacon, and as foundational. Second, in its relationship to ethics: Are we doing in public policy what we are ethically content to do. And finally, does our behavior, administration of our work, reflect our policies properly, effectively. (H.R. Turnbull, videotaped personal communication, December 10, 2014)

In private conversation with Mr. Turnbull, he reiterated that, in some ways, we have succeeded in getting a number of policies and practices in place, but somehow don't know what to do with our success. Although we espouse equality, this does not always result in the same treatment for all.

To further discuss linkages among research, practice, and policy, a social policy report distributed by the Society for Research in Child Development (Supplee & Metz, 2015) elaborates on the state of the art. Although since 2010 the federal government has invested in new evidence-based programs and grant initiatives for children and families, communities must select programs that are applicable and fit the needs of the population in specific environments. We not only need to use evidence-based interventions to gather data to study implementation of practices, but must also use this evidence to inform decision making in policy, especially in the scientific community. We must inform decision makers with a broad synthesis of evidence as well as information about implementation, acceptability, and feasibility, if we are to support effective decision making.

In summary, professionals and advocates working within the fields of research, policy, and practice must think critically about the roles and responsibilities of all the stakeholders in the system

to determine what supports or infrastructure related to context and population are needed to scale up evidence-based interventions and disseminate them widely. Research, practice, and policy professionals must join together to advance the inclusion of individuals with IDD in schools, communities, and workplaces around the globe.

Research Strands

In order to build a research plan, one must have a good idea for research; frame, present, and pursue the idea to a result; and make a compelling case for the idea. Then a research team develops a plan and outcomes and devises products to advance the field or solve a problem, produces feasible knowledge and action plans, and produces/validates/field tests/takes to scale a socially valid intervention. Briefly, I will highlight our work in self-determination and that of others in community living, quality of life, and social capital that has helped to drive practice in the field of IDD.

Self-determination. Our research team at the Beach Center on Disability and the Kansas University Center for Excellence in Developmental Disabilities has been supported self-determination as a viable topic of research for the last 25 years. Beginning at The Arc of the United States in the early 1990s, Michael Wehmeyer and his team of researchers advanced the understanding of self-determination as an individual characteristic of people, infusing this into many areas of life, including transition to adulthood (Wehmeyer & Palmer, 2003; Williams-Diehm, Wehmeyer, Palmer, Soukup, & Garner, 2008); adult services (Wehmeyer & Garner, 2003); employment (Wehmeyer, 2011); access to the general education curriculum (Lee, Wehmeyer, Palmer, & Soukup, 2008); and, most recently, supported decision making in lieu of guardianship (Shogren & Wehmeyer, 2015). We've expanded and supported goal setting and problem solving through a series of self-regulated problems for students to solve via the Self-Determined Learning Model of Instruction (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000), a model for teachers to use in supporting students to set a goal, develop a plan to meet that goal, and evaluate the plan or goal. We've used this model with good results from kindergarten (Palmer & Wehmeyer, 2003) to transition to adulthood (Wehmeyer et al., 2000) by involving the person who is setting the goal in

expressing his or her preferences and abilities, matching these with opportunities, and moving toward goal completion by identifying barriers and an action plan for achievement.

We've also done work on extending self-determination as a construct that has roots in early childhood, where parents and other adults set the stage for learning, self-regulation, and higher expectations for young children with disabilities (Palmer et al., 2013). Given the varied terminology that occurs throughout schools, as parents encounter different bands of services, each year learning about a new classroom and teacher, it would save a lot of time and angst on the part of all participants for parents to be able to voice that they wish their child to be self-determined as they move into adulthood. How can we help to build the capacity of each and every child enrolled in school through encouraging goal setting, effective choice-making, self-regulation, self-monitoring, and self-advocacy? Young children do not have the capacity, nor is it possible for them to be fully self-determined, but they can begin to move through their lives with the support of the environment and the adult setting the context for effective learning (Summers et al. 2014).

We think of self-determination as causal agency, in that through volitional action, agentic action, and action-control beliefs, using needed accommodation if necessary, and by providing opportunities for using self-determined actions, one incorporates volitional action to achieve preferred outcomes (Shogren, Wehmeyer, Palmer, Forber-Pratt, Little, & Lopez, in press). Acting as a causal agent, essentially, so that if someone has encouragement and support to make choices and decisions and set and achieve goals, they can be self-determining. The work of Wehmeyer and colleagues has extended the initial research on self-determination and transition to adulthood to all areas of functioning, infusing self-determination into a number of activities such as employment, community living, and building social capital (Palmer, 2010).

Quality of life. The result of living a self-determined life in the community and place of your choice will be an enhanced quality of life of one's choosing. The work of Schalock and others in this area of research, practice, and policy has expanded the opportunity, context, supports, and personal well-being of people with IDD, support-

ing them to experience the dignity of risk (Reinders & Shalock, 2014).

Community living. Amy Hewitt, outgoing AAIDD President, described expectations for adults to live in the community, working at real jobs for real wages, making choices/taking risks, and accepting responsibilities of citizenship (Hewitt, 2014). Through the research, practice, and policy work of the Research and Training Center (RTC) on Community Living, we have a much better understanding and plan for adults to be involved in their community, with adequate supports and services. Figure 1 lists a number of these elements that lead to full community participation.

Social capital. Building social capital is also important. Although there are a variety of definitions of social capital, there is an “emerging consensus that social capital, at its core, comprises a set of relationships and social structures” (Gotto, Calkins, Jackson, Walker, & Beckmann, 2010, p. 1). One can have expectations for individuals to be a part of communities, and we must hold up the following ideas to support individuals to participate fully. Ann Turnbull speaks eloquently about the

way that we can support people with IDD to be more fully involved in the lives of people around them, building social capital in very practical ways.

Inviting people into the lives of people with disabilities, ensuring that they have a way to contribute, but not overwhelming and wearing them out. And then, secondly, teaching and supporting people with disabilities to care about the choices and preferences of other people, and to know that social relationships are reciprocal and that [people with disabilities are] not always the center of attention themselves. And then, three, looking into the community and to what are the organizations [that] typically provide social networking for others, and how we can invite people with disabilities in and provide them with the support and the individual connections to truly thrive. (A.P. Turnbull, videotaped personal communication, December 11, 2014)

I want to thank Ann and Rud Turnbull for sharing their wisdom and experience with us today through

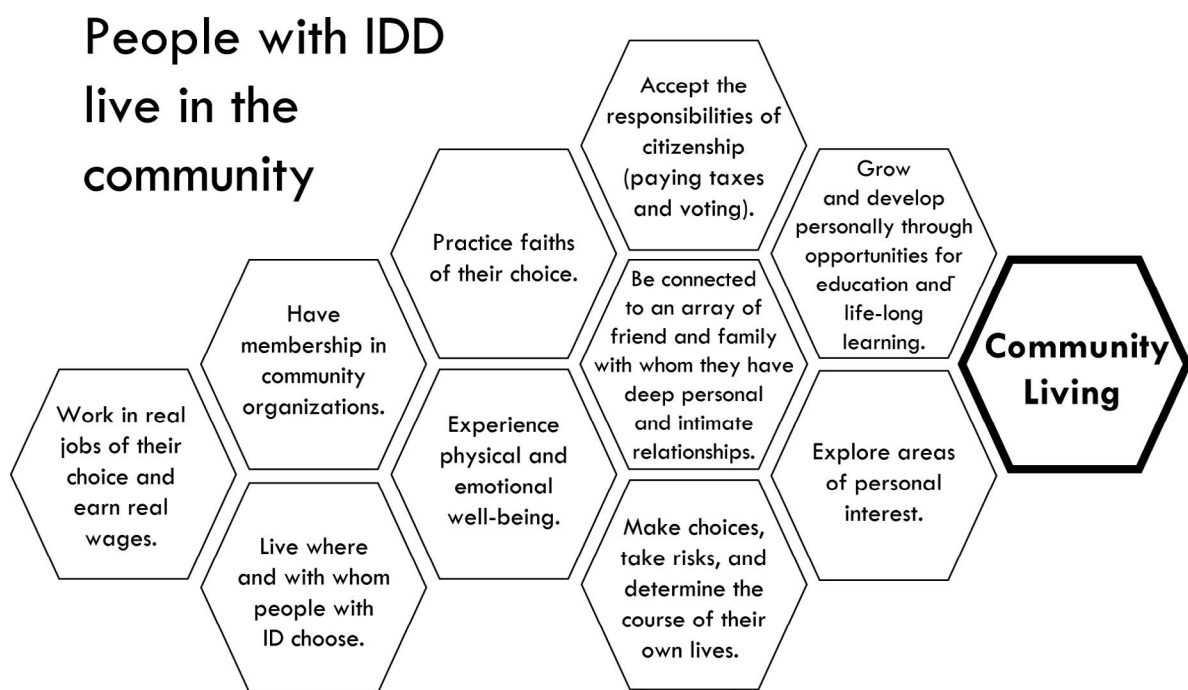


Figure 1. Elements of community living. Adapted from Hewitt, A. (2014). Presidential address, 2014—Embracing complexity: Community inclusion, participation, and citizenship. *Intellectual and Developmental Disabilities*, 52(6), 475-498. Used with permission.

video. We have also been fortunate to have them with us during the 2015 conference in Louisville.

Integration of Research, Practice, and Policy

One way we can collectively solve problems as groups of researchers, practitioners, and policy-focused individuals is to integrate, connect, collaborate, and expand our perspectives. Often there are different cultures within research, social policy, and practice-related work. One example of a melding of perspectives is work initiated in the field of child development by Jack Shonkoff at Yale University (Shonkoff, 2000). Dr. Shonkoff asked basic and applied researchers, practitioners, and policy-focused organizations and members to work toward integrating the three disciplines of research, practice, and policy to advance the field of child development. Currently, AAIDD is at a flash point to navigate across the borders of research, practice, and policy to understand the different rules of evidence, to speak the distinctive languages, and to achieve credibility in all three worlds while maintaining a sense of intellectual integrity in each area through a shared mission. AAIDD provides the linkage necessary to build this capacity. Our well-respected journals and communication links with membership in our organization and other organizations help to position us as a cutting-edge association, poised to be at the nexus of research, practice, and policy.

But, much like last year's conference theme in Orlando, complexity is the rule, rather than the exception. We must work together as a group of professionals to connect what we know about research, practice, and policy if we are to make a difference. Rud Turnbull again tells us about some important work in the area of family-professional partnership that I believe we can use to expand partnership within the community of organizations related to disability.

The third matter that I want to address very briefly has to do with the relationships between parents, family members, on the one hand, and professionals on the other. And when I say family members, I include of course, individuals with disabilities— particularly them. Ann Turnbull and I have done a good deal of writing about this matter of partnership, and there seems to us to be seven elements of

it. I'll list all and then I want to talk about one in particular: communication, commitment, capacity to do the job, advocacy, respect, the sense of equality, and trust.

This matter of trust is essentially the lynchpin that holds all of the six elements together; it's the keystone of the arch. Why is trust so important? It simply is important because we cannot proceed together, either as an individual with a disability, a professional, or a family—we cannot proceed together effectively without being able to trust each other. You can take all the legal mechanisms that we lawyers can devise, and write it all down, and sign all these agreements, and do all of the formalities. Those are ceremonies and they are important ceremonies, but they are ceremonies nonetheless. What they should express is this notion that we trust each other; and here I speak not only as a professional and a lawyer, but also as the father of a man who died 6 years ago, who had intellectual and other developmental disabilities. Had he not trusted us and had we not trusted his judgment about himself, and if we had then not been able persuade professionals to trust him and us, his life would have been far less joyful, far less of high quality, and far more oppressed. (H. R. Turn-

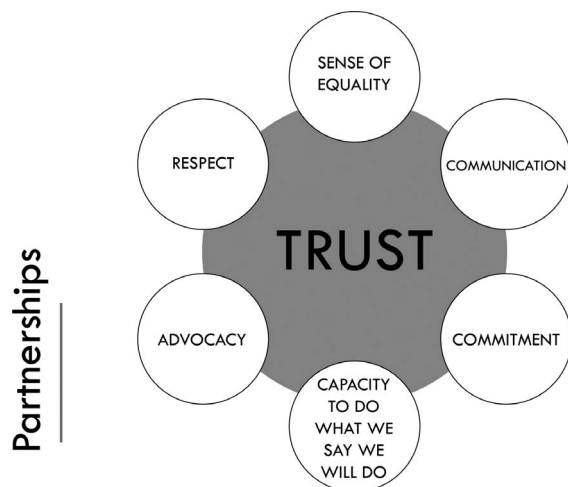


Figure 2. Trust links and sustains elements of partnership. Excerpted from H. R. Turnbull videotaped personal communication, December 10, 2014.

bull, videotape of personal communication, December 10, 2014)

AAIDD can use Mr. Turnbull's analogy of TRUST to guide partnership between families and professionals involving individuals with disabilities and providers as seen in Figure 2 to expand our horizons to work toward partnerships with other entities, either research, practice, or policy units or disability-focused groups that are in existence. If we wish to work in partnership with others, TRUST is the lynchpin, the cornerstone, the most important element to consider along with respect, supporting a sense of equality, common commitment, a capacity to do what we say we will do, and advocacy for perspectives that support our mission.

AAIDD Past and Present

The wheel in Figure 3 represents the connection of AAIDD membership with a number of other disability-related organizations. We as a group hold

AAIDD Members in Disability-Focused Groups

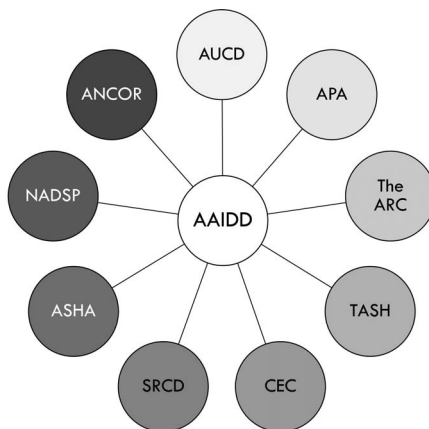


Figure 3. AAIDD members are part of multiple disability groups. This figure lists just a few of the disability-focused organizations to which AAIDD members belong: American Speech and Hearing Association (ASHA); American Network of Community Options and Resources (ANCOR); American Psychological Association (APA); The Arc; Association of University Centers on Disabilities (AUCD); Council for Exceptional Children (CEC); National Alliance for Direct Support Professionals (NADSP); Society for Research on Child Development (SRCD); and TASH, an advocacy group for full inclusion.

membership in many varied organizations and can be involved in informing and supporting the work of AAIDD in research, policy, and practice. The alliances we as members form, and connections and collaborations we engage in, are viable channels of interaction and influence that can further support AAIDD as a cutting-edge organization and leader in the field of IDD.

When we look to the past, 25 years ago James Ellis was president of the association and in his address to the group (Ellis, 1990) he spoke of assessing the impact of intellectual disability (ID), rights for people with ID, public policies to enhance integrations, and awareness of sources of threats to the freedom and safety in the lives of people with ID. Terms used in this speech, including mental retardation and normalization, have gone by the wayside. But Medicaid reform, abuse and exploitation of people with ID, social indifference to the needs of people with ID, and need for death penalty legislation and intervention are still in our current thoughts and agendas. We must continue the mission to support the health, welfare, independence, and community integration of people with ID. With this 25th anniversary of the Americans With Disabilities Act (ADA, Pub. L. 101-336, 1990), we can see how this basic civil rights law to provide barrier-free environments in public places has impacted individuals with IDD. However, Nelson (2015) reminds us that we need to continue to strive for community accessibility or inclusion by building and supporting interpersonal relationships with individuals with disabilities, building within existing cultures of everyday activities where individuals are part of what is happening around us, and striving for personal validation for people with IDD within our culture so that expectations are high for them to be part of everyday life.

AAIDD's Mission for Leadership

The mission statement of AAIDD is this: "AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities." Our goals include the following: 1) enhance the capacity of professionals who work with individuals with intellectual and developmental disabilities; 2) promote the development of a society that fully includes individuals with intellectual and developmental disabilities; and 3)

sustain an effective, responsive, well-managed, and responsibly governed organization. The first of AAIDD's principles guiding achievement of goals relative to the mission statement is, "Cultivate and provide *leadership* in the field of intellectual and developmental disabilities that encompasses a diversity of disciplines, cultures, and perspectives." One principle of leadership is that, first, you have to lead yourself by self-monitoring: building relationships, planning, capturing ideas, taking care of technology, checklists, meetings, and reading habits (Bock, n.d.). Beyond this, leaders engage in innovation, which is an ongoing process. Innovation is an advantage, until others copy what you've done . . . or the next big thing replaces it. Thus, innovation must be an ongoing process.

Leadership is intangible. What do good leaders do? As a good leader you would: listen attentively and respectfully; ask thoughtful questions to expand knowledge of an issue; use perspective taking; keep informed about new trends in your field; synthesize important information from documents and reports; provide feedback to others in a direct, respectful, and supportive manner; show concern and empathy for others, with an appropriate level of emotion; and find common ground on divisive issues. Further, leaders are open and inclusive; know what they do not know; surround themselves with informed people who do know; and finally realize that failure is part of leadership, but that risks lead to great rewards.

When I want to know more about leadership within the field of IDD, I often visit my colleagues and friends at The Arc of Douglas County and the Self-Advocate Coalition of Kansas. Barbara Bishop, Executive Director, is a person I admire because she has the vision and ability to support people with IDD within community settings with ease. She often mentions that SHE works for the Self-Advocates of Kansas (SACK) doing their financial statements as treasurer, but THEY are in charge of their activities, beyond budgetary limitations.

Speaking of budgets, the state of Kansas is currently (as of the time of the annual meeting in June, 2015) in a serious shortfall of revenue from a master plan by our governor's administration to cut taxes to build infrastructure and boost business. I don't want to talk about the politics of these actions except to say the activities at the legislature are severely impacting the ability of people with IDD and the families of people with disabilities to function to the best of their ability. In addition, the

funding stream for the self-advocates of whom I speak has been in limbo, waiting on the actions of the legislature to pass their budget. Although the state Senate and House agree that there is a need to fund SACK and a line item exists, in these last days of budget cutting, it is difficult to imagine that their funding will be maintained at the current rate for the coming years.

The group knew that funding was in jeopardy and, after a brief period of recovery from shock, began to make alternate plans for funding alternatives. Brad talked about how the group had some champions in the state and community and had made connections with the Kansas Leadership Center in Wichita, Kansas, which included at least two members of SACK in a community-based cyclical group training and collaboration session every several months. Through this training, Stephanie, self-advocate advisor, and other group members, including Kathy, Hal, Kelly, and Cole, learned to think differently in terms of diversification of funding and planning, to approach problems with a more balanced plan of working through challenges. As I listened, I knew that I would be sharing this information with you today, to ask you all to think in like fashion about the challenges and difficulties you face in your professions and the work that you may do with and on behalf of people with IDD in your home states and universities.

We need to take our cue from SACK and learn to rethink how we approach leadership. Rather than moving to default mode and waiting for this or that element to change in what we do, we should try new paths to energize and rework our plans, so that we maximize resources and become less dependent on the publicly funded mandates to manage what we do. In other words, we must rethink our default mode of operation if we are to eliminate the following less-functional pathways: a) new activities would take too much of our time; b) we don't have the funding for that now, we need to wait; or c) people need to realize that the system is inadequate and we cannot do anything else until. . . . Instead, we need to be more resilient and do what we should be doing in reinventing a new and better way to operate through our strengths and what we do best—lead with our whole heart and lead to work around restraints and barriers to come up with newer and more user-friendly ways to support individuals with IDD and their families, who tend to be at the

mercy of the budget and policy alterations, as well. [Update as of September 2015: SACK is now grateful that their consortium has been level-funded from June, 2015, to May, 2017, but with no increase in allotment during this period.]

One example of leadership to eliminate barriers comes from the state of Missouri, where my friend and colleague, George Gotto, collaborates with a state-initiated group called Missouri Self-Determination Association (MO-SDA; <http://mo-sda.org/>). This is a work group with the sole purpose of infusing self-determination into adult services in such a way that choice, interests, and unique opportunities were more the norm, rather than the exception for many agencies. The state Division of Developmental Disabilities used a voluntary model of instigating this work, since they reasoned that if a unit had no interest, above gaining a limited number of funds for this purpose, they would probably not be effective implementers of services. This type of leadership example and follow-through on behalf of individuals with IDD serves as a good example of positive outcomes that emerge when groups work through barriers to make change.

Henry Kissinger (n.d.) wrote, “The task of the leader is to get his people from where they are to where they have not been.” We at AAIDD, both membership and leadership, could take this advice and channel the opening narration of each episode of *Star Trek*, “To boldly go where no man [or woman] has gone before...” (*Star Trek*, n.d.), meaning that we have to move out of our comfort zone and initiate change for the better of the people we know or will know with IDD who deserve better than Mike Wehmeyer’s 1980s analogy of many of our services and supports. It’s 2015 and time to move forward!

As an organization and as participants in the active pursuit of research, practice, and policy, we are still searching for the best manner to proceed to excellence. Martin Seligman and his colleagues, in *Navigating Into the Future or Driven by the Past*, focused on prospecting, or the representation of possible futures as a feature of the human mind (Seligman, Railton, Baumeister, & Sripada, 2013). Although much psychological theory and practice is determined by the past, a suggestion of looking to the future as a core organizing principle of animal and human behavior is hopeful and perhaps what we should be doing within AAIDD as a current model of prospecting—a thought process to move us into the future. We are fortunate to have Maggie Nygren

as our Executive Director of AAIDD. Maggie is a professional in the disability field in her own right, and represents us extremely well within our national and international organization by networking, collaborating, and prospecting the future for additional sources of revenue beyond the current SIS and publishing activities of the association. We have an enduring past at 139 years, but also need to take stock regarding the future.

Final Thoughts

AAIDD is a historic organization that has roots in the medical and behavioral models, with membership previously based in management of institutional settings. We became a group with many layers of membership at the state and regional levels with a multitude of special interest groups. Currently, we are best identified by a more targeted membership that focuses on IDD and community inclusion in work, living arrangements, and building social capital within settings where everyone is involved. We do not focus on a particular theoretical model; we reach out to other organizations and engage in networking for the benefit of people with IDD, and work collaboratively to achieve a common goal of full inclusion. Looking to the future, honoring the past, but moving forward without restraints of past models and old barriers to success will benefit not only the association, the AAIDD membership, but also individuals with IDD and their family members. Speaking of family members, I want to thank my husband, Dennis, for all his support, encouragement, and help throughout the years. He is my inspiration, along with our children and grandchildren.

Thank you for your attention today. I want to close my remarks with heartfelt thanks to all of you who have been involved in networking, attending sessions, getting up early to meet with special interest groups and divisions, and supporting AAIDD through your work as professionals in the areas of research, practice, and policy.

References

- Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327, codified at 42 U.S.C. § 12101

- Bock, W. (n.d.). *Leading yourself: A baker's dozen of things to master*. Retrieved from <http://www.threestarleadership.com/leadership/leading-yourself-a-bakers-dozen-of-things-to-master>
- Education for all Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773, codified at 20 U.S.C. § 1400
- Ellis, J. W. (1990). Presidential address 1990: Mental retardation at the close of the 20th century: A new realism. *Mental Retardation*, 28, 263–267.
- Gotto, G. S., Calkins, C. F., Jackson, L., Walker, H. & Beckmann, C. (2010). *Accessing social capital: Implications for persons with disabilities*. Retrieved from http://ngsd.org/sites/default/files/accessing_social_capital_implications_for_persons_with_disabilities.pdf
- Hewitt, A. (2014). Presidential address, 2014—Embracing complexity: Community inclusion, participation, and citizenship. *Intellectual and Developmental Disabilities*, 52(6), 475–498. <http://dx.doi.org/10.1352/1934-9556-52.6.475>
- Hoagwood, H., Burns, B. J., Kiser, L., Ringeisen, H., & Schoenwald, S. K. (2001). Evidence-Based practice in child and adolescent mental health services. *Psychiatric Services*, 52(9), 1179–1189. <http://dx.doi.org/10.1176/appi.ps.52.9.1179>
- Individuals With Disabilities Education Act, 20 U.S.C. §§ 1400 *et seq.* (2006 & Supp. V. 2011)
- Kissinger, H. (n.d.). Henry A. Kissinger quotes. Retrieved from <http://www.brainyquote.com/quotes/quotes/h/henryakis130663.html>
- Lee, S. H., Wehmeyer, M. L., Palmer, S. B., & Soukup, J.H. (2008). Self-Determination and access to the general education curriculum. *Journal of Special Education*, 42(2), 91–107. <http://dx.doi.org/10.1177/0022466907312354>
- National Implementation Research Network. (n.d.). *About NIRN*. Retrieved from <http://nirn.fpg.unc.edu/about-nirn>
- Nelson, L. L. (2015). What accessibility means in its fullness. In V. Gaylord, C. Wieck, M. Nalker, & A. Hewitt, & C. Poetz (Eds.), *Impact: Feature issue on the ADA and people with intellectual, developmental, and other disabilities* (p. 31). Minneapolis, MN: University of Minnesota, Institute on Community Integration.
- Palmer, S. B. (2010). Self-Determination—A life-span perspective. *Focus on Exceptional Children*, 42(6), 1–16.
- Palmer, S. B., & Wehmeyer, M. L. (2003). Promoting self-determination in early elementary school: Teaching self-regulated problem-solving and goal-setting skills. *Remedial and Special Education*, 24(2), 115–126. <http://dx.doi.org/10.1177/07419325030240020601>
- Palmer, S., Summers, J. A., Brotherson, M. J. E., Erwin, Maude, S., Stroup-Rentier, V., Haines, S. (2013). Building a foundation for self-determination in early childhood: An inclusive model for children with disabilities. *Topics in Early Childhood Special Education*, 33, 38–47. <http://dx.doi.org/10.1177/0271121412445288>
- Practice. (n.d.). In *Dictionary.com*. Retrieved from <http://dictionary.reference.com/browse/practice>
- Reinders, H.S., & Schalock, R. L. (2014). How organizations can enhance the quality of life of their clients and assess their results: The concept of QOL enhancement. *American Journal on Intellectual and Developmental Disabilities*, 119(4), 291–302. <http://dx.doi.org/10.1352/1944-7558-119.4.291>
- Research. (n.d.). In *Dictionary.com*. Retrieved from <http://dictionary.reference.com/browse/research>
- Salyers, M. P., Becker, D. R., Drake, R. E., Torrey, W. C., & Wyzik, P. F. (2004). A ten-year follow-up of a supported employment program. *Psychiatric Services*, 55(3), 302–308. <http://dx.doi.org/10.1176/appi.ps.55.3.302>
- Schoenwald, S. K., & Hoagwood, K. (2001). Effectiveness, transportability, and dissemination of interventions: What matters when? *Psychiatric Services*, 52(9), 1190–96. <http://dx.doi.org/10.1176/appi.ps.52.9.1190>
- Seligman, M. P., Railton, P., Baumeister, R. F., & Sripada, C. (2013). Navigating into the future or driven by the past. *Perspectives on psychological science*, 8(2), 119–141. <http://dx.doi.org/10.1177/1745691612474317>
- Shogren, K. A., & Wehmeyer, M. L. (2015). A framework for research and intervention design in supported decision-making. *Inclusion*, 3, 17–23. <http://dx.doi.org/10.1352/2326-6988-3.1.17>
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A., Little, T. J., & Lopez, S. J. (in press). Causal agency theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities*.

- Shonkoff, J. P. (2000). Science, policy, and practice: three cultures in search of a shared mission. *Child Development, 71*(1), 181–187. <http://dx.doi.org/10.1111/1467-8624.00132>
- Star Trek. (n.d.). *The origins of 11 famous Star Trek lines*. Retrieved from <http://mentalfloss.com/article/50607/origins-11-famous-star-trek-lines>
- Summers, J. A., Brotherson, M. J., Erwin, E. J., Maude, S. P., Palmer, S. B., Haines, S., Zheng, Y. (2014). Family reflections on the foundations of self-determination in early childhood. *Inclusion, 2*(3), 175–194. <http://dx.doi.org/10.1352/2326-6988-2.03.175>
- Supplee, L. H., & Metz, A. (2015). Opportunities and challenges in evidence-based social policy. *Social Policy Report, 28*, 1–16.
- Wehmeyer, M. L. (2011). What is next in the transition and employment movement? *Journal of Vocational Rehabilitation, 35*(3), 153–356.
- Wehmeyer, M. L., & Garner, N. W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities, 16*(4), 255–265. <http://dx.doi.org/10.1046/j.1468-3148.2003.00161.x>
- Wehmeyer, M. L. & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities, 38*(2), 131–144.
- Wehmeyer, M. L., Palmer, S. B., Agran, M., Mithaug, D. E., & Martin, J. (2000). Promoting causal agency: The self-determined learning model of instruction. *Exceptional Children, 66*(4), 439–453. <http://dx.doi.org/10.1177/001440290006600401>
- Williams-Diehm, K., Wehmeyer, M. L., Palmer, S., Soukup, J. H., & Garner, N. (2008). Self-determination and student involvement in transition planning: A multivariate analysis. *Journal on Developmental Disabilities, 14*, 25–36.

Author:

Susan B. Palmer, University of Kansas.

Correspondence concerning this article should be addressed to Susan B. Palmer, Beach Center, KUCDD, University of Kansas, 3136 Haworth Hall, Lawrence, KS 66045-7634 (e-mail: spalmer@ku.edu).