

## Presidential Address, 2016—Re-Membering the Gifts of Professional

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Who are we as the American Association on Intellectual and Developmental Disabilities (AAIDD)? How would you answer that? If we stopped right now and had table discussions on that question, there is no telling what would come up. You might say:

- The oldest professional organization on intellectual and developmental disabilities
- A publishing house
- An advocacy organization
- An assessment organization
- A very diverse collection of professionals in many different roles

You name it. We might have a broad consensus of who we are, or the description might be more like the classic metaphor of seven blind men trying to describe an elephant, with each of them feeling a different part of that magnificent creature.

Last year, Susan Palmer addressed our roles in research, policy, and practice. Many of us would cite those three bastions as definitive of AAIDD mission, purpose, and identity. I often try to describe AAIDD as supporting a three-legged stool in each state: a developmental disability (DD) council; protection and advocacy; and one or more University Centers for Excellence in Developmental Disabilities (UCEDDs), Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, or research centers. At our best, research, policy, and practice—the three pillars of AAIDD—interact dynamically with one another in ways that help keep the whole enterprise, and our professional roles, balanced. At our worst, there is an uneasy relationship between the three, with advocates who identify primarily with one of those legs sometimes thinking and saying, “If only you two were more like me.”

You would not want to stand on a two-legged stool. At our best, that relationship between research, policy, and practice is neither a hierarchy nor separate bastions, but a constant process of what we in the world of clinical pastoral education

call an “action/reflection process.” We come to practice with what we know, partly shaped by research foundations and policies that impact our practice. That practice leads to the need for more research and more effective policies, which then can be tested out in practice. The three operating as one, but each distinct. (If I sound like a theologian trying to slip in a lesson on the workings of the Trinity, I assure you that I am not.)

Some of you may know a similar process in Essential Lifestyle Planning, the 4+1 questions (Smull, 2011):

1. What have we tried?
2. What have we learned?
3. What are we pleased about?
4. What are we concerned about?
5. Given what we know now, what next?

However it is described, the process of critical reflection and research on policy and practice is fundamental to keeping a system of services and supports alive and growing. A process of self-evaluation, critique, and reflection with other peers (i.e., peer review), is a core part of what we understand “professional” to mean. We know and keep learning about *what* should be done, *where* and *when* it should happen, and *how* things best work. In his presidential address in Pittsburgh, Jim Thompson (Thompson, 2013) talked about three new professional imperatives that the social model of disability calls us to explore:

1. Understand each person holistically, with particular sensitivity to the fact that all people have relative strengths to go along with relative impairments.
2. Focus professional efforts on arranging personalized supports that bridge the gap between any limitations in personal competency and the demands of settings and activities. (My comment: One form of professional as bridge-builder is built right into that role.)

3. Recognize that empowering people with disabilities to live full lives in their communities not only enhances the quality of life of people with disabilities but also enables the general population to experience the contributions and richness that people with disabilities provide to their communities.

Since his 2013 address, it is even clearer that the stories of disability are intimately tied up in the stories of diversity, and the wider cultural question of whether we are going to be a country and world that appreciates and gives thanks for diversity or one that is threatened by the very diversity that is at the heart of creation. Jim Thompson went on to define AAIDD's primary roles as furthering knowledge, mentoring, and *promoting engagement* (emphasis intentional).

### Why and Who?

We have occasionally talked about why we do what we do. Bob Schalock (1998) explored some of those “whys” in his presidential address, entitled “A Personal Odyssey: The Story Behind the Story” (Schalock, 1998). I would submit that our attention to the why we do what we do is somewhat limited, far too often answered only with “that’s what we are paid to do,” “where the funding is,” “it’s what we are told to do,” and/or “that’s the way we have always done it.” We are getting much better, I hope, at practicing what we preach in our person and family-centered values: We do it because this is what individuals and families both need and want or, as said more eloquently by Essential Lifestyle Planning (Smull et al., 2009), by listening deeply to what is “important to” someone as well as what is “important for” them. But there are other dimensions of the “why” that ask us to explore and speak from our motivation, values, and sense of call and vocation. Very few people have the space and invitation to do that kind of reflection, especially during work time, yet it is the kind of sharing and communication that speaks deeply and moves us under the surfaces of evidence-based practice to times for rethinking and rekindling our own “whys.” (Basmat Ahmed challenged us to that kind of reflection yesterday in the first plenary discussion on community building.)

But even more striking in these processes of building professional capacity and effective services

is that the question “Who are we as professionals?” is greeted by even shorter attention spans. Who are we as people in our various professional roles? In AAIDD, we may each have a professional identity, illustrated in the variety of disciplines represented in the Conference of Professional Interests, or in the topic or arena that is the focus of our individual work. In that question of identity lay the questions of why did you choose this particular profession, as well as who and what framed that choice and helped form and mold you to be the person and professional you now are. (Some of us might frame that in reverse and talk about how this or that profession choose me.) Many of us have a certification, degree, or title that says “this is who I am” or “who I am trying to be.” But ever since “professionals” arose out the guilds of the Middle Ages, the understanding of “professional” has increasingly evolved (or devolved) to mean the knowledge we have mastered and the skills we can demonstrate, with a corresponding reduction in focus on the processes of identity formation, mentoring, and apprenticeship that are still so crucial to our individual development.

That evolution eventually led to an understanding that the meaning of “professional,” explicitly or implicitly, is one who is able to separate his or her values from his or her professional role. That result came, I think, from a continued focus on scientific objectivism, as well as a reaction against the evils of the misuse of professional position and power for proselytizing purposes of one kind or another. One consequence, however, was that the definition of “professional” was by and large captured by the medical model of disability.

That model, in turn, was challenged by the evolving social models of disability with the inclusion of many more disciplines under the rubric of disability studies—disciplines like philosophy, art, English, history, theology, and others that have always spoken to, and reflected upon, the importance of meaning and values. Community inclusion and citizenship also pushed “professional-centered planning” to “person-centered,” or, as someone said this morning, “person-driven” planning. Professional prestige and power shifted to the empowerment of those whom we had called patients, residents, and clients. Our places of practice shifted from clinic to community. In the field of mental health, some professionals have begun identifying themselves as “recovering professionals.” In ours, professionals are

seen in a multiplicity of roles from a variety of perspectives. That's what so intrigued me about the four collages of professional staff made by the participants of the WAE (Wellness, Arts, and Enrichment) Center (2016) of West Orange, New Jersey, that grace the cover of our conference program. We are seen from many angles and inflections, so that looking at "professional" is much more like using a kaleidoscope than a microscope.

### **The Challenges of Community Inclusion and Person-Centered/Family-Centered Care**

Our opening plenary on community inclusion and the one this morning on the perspectives on professionals from families, siblings, and advocates have highlighted the two areas that I think bring the biggest challenges to current professional roles and our own sense of professional identity. When both the arena and objective of our practice is true community inclusion, what does it mean when the people we serve and support are now our fellow citizens, neighbors, employees, and members of congregations and other organizations to which we may belong? Whose job is it to facilitate community inclusion? Both practice and research tell us that it cannot simply be relegated to one or two persons with the role of "community facilitator." With families, siblings, and self-advocates, the professional role cannot simply be diagnosis, assessment, and referral. Those are crucial and very powerful roles, ones with real consequences that should lead to an even deeper awareness of our own responsibility. But we will also interact with people in many more places than one, and through many more roles.

We all know the blessing and curse of labels, the relief of knowing what you are dealing with but also the danger of defining a person's identity by a single word. Perhaps you have seen Nigerian novelist Chimamanda Adichie's TED Talk that went viral, "The Danger of a Single Story" (TED, 2009). None of us is a single story. Add to that the fact that assessments often determine eligibility and, thus, serve as gateways into the worlds of public services or, more typically, to the end of a waiting list. Nor can a professional be someone simply and naively providing a specific, specialized service or support that requires specialized training because one of the unintended consequences of

that identity has been the disempowering of community capacity to care with and for people with disabilities, i.e., the assumption that you had to have some sort of "special training," in addition to your being "such a special person," to have relationships with "those people." If you have not read it, the classic essay by John McKnight (1984) entitled "John Deere and the Bereavement Counselor" highlights the ways we have professionalized the capacity of communities to grieve, mourn, and support one another. Systems and communities use different lens and have different priorities. The paradox in that systems and services, we are focused on clients first, needs second, and services third, but community is built by seeing persons first, gifts and strengths second, and relationships third. The second plenary puts us face to face with the challenges of practicing what we preach in person-centered and family-centered supports and services. It means listening in new and deeper ways to individuals, families, and siblings. Listening has to be more than assessments, although it does start there. Do you know the Latin root meaning of the word "assessment?" It is "to sit next to." We tend to see assessments as objective measures (i.e., over or against), although to do a good Supports Intensity Scale (SIS) assessment, you do have to "sit next to" for a while. "Sitting next to" is the first real challenge to professional boundaries and distance. But "sitting next to" involves compassion and action, what sociologist and theologian Nancy Eiesland called "just listening": listening with an ear for more than the needs and gifts of another, but also an ear for justice, the issues that may call us beyond our identified professional boundaries and roles and our usual tendency to jump in quickly with a prescription or a fix (Eiesland, 2001). "Just listening" implies a commitment to continuity of action and community; action over time in the communities in which we live; action related to policies, structures, and communities in which relationships are built, sustained, and celebrated.

### **Two Key Questions About Inclusion and Relationship**

In the last year, two conversations with parents have crystalized issues for me that have enormous implications for professional roles. In one conversation, a parent whom I have known for a long

time, the mother of a young woman who has aged out of school, a parent who has fought for inclusion every step of the way, noted that if inclusion was to happen now for her daughter, it seemed that she and her husband were the only ones who felt any responsibility for that. No one else steps in, a situation heightened if a family has moved. Who takes initiative, if not paid, to help connections, community presence, and friendship happen? Not just the initiative, but sustained commitment over time? A favorite African proverb of mine is “When there is a thorn in the foot, the whole body has to stoop to take it out.” The task of inclusion is not to take out, but to put in; in either case, it takes a village, a “body” to which one is connected, or, at least, a very good circle of support.

Second, over a cup of coffee in Waco, I asked the mother of a middle-school-aged son on the autism spectrum, “Who has been helpful to you all over time?” She named one professional they had met relatively early in her son’s life, and then noted, “he is the only one who has not abandoned us.” Similar to the rapid turnover in the direct care world, might we need to ask if there are not truly harmful side effects of another form and process of far-too-rapid turnover for parents. This one comes not so much from staff leaving but from professional referring or withdrawing, however, it must seem to some like an endless cycling of trust, promise, departure, and disillusionment.

So let me explore the implications of (1) community building and inclusion and (2) continuity of care and relationships, in some more detail and with a few specific proposals. They are both ways, as Jim Thompson said, of *promoting engagement*.

### **Community Inclusion and Community Building**

First, community inclusion and community building. In preparation for this plenary, I was in an email conversation with Trace Haythorn, the father who was on our panel this morning. He had listened to a webinar on grief, loss, and intellectual and developmental disability that another chaplain and I had done for the Association of Clinical Pastoral Education, and commented that he had never felt “on guard” as we did the webinar. So I asked about that, and he talked about parents having to be on guard for what others might say about their child at any point. He told me about a pet peeve that so

many families and people with disabilities will identify with: people talking to him about his daughter, Martha, when she was right there. We talked about a specific relationship in his office building with a friendly security guard who always wanted to ask something about Martha, but always addressed Trace instead of Martha. So I did what professionals often do—give advice when someone had not asked for it—and wrote that, perhaps the next time that happens, he simply say, “I don’t know. Why don’t you ask Martha herself?” Trace then reflected on his own actions and quoted back to me a saying from Greg Ellison, an African American theologian and activist at Candler. One of Greg’s mottos and fallback positions is a life lesson learned from his auntie, who said “Greg, I may not be able to change the world, but I can change the three feet around me” (Ellison, 2013).

We have finally learned some things about community building. It took me years to see what was hidden in plain sight—that people build relationships out of shared passions and interests, not out of helping and being helped. We know it does not work if we give all of the community building responsibilities to one or two staff in a provider agency. What if we re-visioned all of our professional roles not simply around a policy vision of inclusion but as inclusive of community building as one of our roles? What if we saw our own organizations not simply as a directory of specialized services, but as resource banks of interests and passions that could be turned into connections, introductions, and invitations, using John O’Brien’s eloquent observation that “the quality of our lives depends on the quality of our introductions and our invitations” (O’Brien & O’Brien, 1996).

Dream for a minute how that would work. Good person-centered planning is based on what is “important to” as well as what is “important for.” “Important to” includes passions, interests, hobbies, dreams. The people in that person-centered planning meeting or doing direct support may not know who in the community might have similar kinds of interests, but someone in accounting, human resources, or any other section of the organization just might be the one who knows.

So, for example, if someone’s passion was opera music, and if community building was in the fiber and blood of a provider organization, could not someone, coming out of the person-centered

planning meeting with the responsibility to help follow through, say to the whole organization, “We are looking for someone in our organization who knows someone who is interested in opera music or knows someone who is.” Six degrees of separation starts three feet in front of us, right at our organizational homes. And then, could the one who knew someone, or another staff person who no one knew was an opera aficionado, start figuring some ways to make some introductions and connections.

Doing so begins with what I sometimes call “reversing the tragedy.” The tragedy is not the person’s disability. The tragedy, in this scenario, is that he or she never has a chance to listen to opera music with someone else, much less get to attend an opera performance. That’s what any opera fan would tell you. Then, the community-based opera lover is being asked, or invited, to get to know someone out of something they know a lot about, out of their capacity, rather than feeling disempowered because of lack of knowledge about disability. The staff person (from whatever role in the agency) who helps make the connection and introduction has to convey something usually considered very unprofessional: They have to convey that they will help as much as needed with questions around the disability, but they don’t know anything about opera and are certainly not the experts. One might also say it is the most professional thing one can do and be: *To know what you don’t know, don’t pretend otherwise, and be willing to use it by asking for help.*

Take the dream a bit further, and think what would happen if everyone in an organization took responsibility for one person served by the agency to help those kinds of connections happen. “Each one, take one,” and learn how to use the social capital starting three feet in front of them to begin to make connections happen. There are some other critical reasons for doing so. Direct support staff would see managers, administrators, and clinicians working with them and taking on the one-to-one work of inclusion. Moreover, those managers, administrators, and clinicians are most likely to be the ones with more social capital in the communities served by that provider, especially when so many direct support workers are immigrants trying to figure out community in America at the same time. The public relations and public awareness impact would be huge.

## Relationships Over Time

Second, continuity of care, or sustainability of care, over the long haul. My thinking about this did not first start with the omnipresent question for so many families, “Who will watch and care over the long haul?” No, it started first as a chaplain doing funeral services in an institution, and then, for close to 15 years, doing workshops and consultation in New Jersey for staff of all kinds on coping with grief, loss, and end-of-life issues. The quality of a funeral may often depend on how one ages. The questions in the workshops not only revolved around how best to recognize and allow people to mourn someone’s death, but also, “Who was going to mourn that person’s death?” Which also then raised the questions, “How did someone age? In relationships, or alone?”

What are the core tasks of aging? A Park Ridge Center study on the universal tasks of aging outlines five areas that are common across spiritual traditions (Park Ridge Center, 1999). As we age, how do we:

- Reaffirm and reconnect with and to community, i.e., friendships, connections, memories.
- Bless those who come after you . . . how have you been that, done that, and given that?
- Maintain honor in aging, dignity, respect, appreciation.
- Maintain faith and hope in face of loss.
- Reconcile discordant experiences, e.g., letting go, reunions, forgiving.

In our aging services and supports, each one of these areas raises questions for quality services and supports. But I want to hone in on one. How does someone in our services know that their life has made a difference? Have they been able to give a blessing and affirmation to those coming behind them?

Or, more poignantly, when people often live lives without many close friends, who is going to let them know that they have been a blessing to others? Beyond inclusion is belonging. Belonging means you will be missed. Who is going to tell someone that? Far too often, professionals are the only ones besides family members and other adults with intellectual and developmental disabilities who have known someone over time. How do we deal with professional grief and loss or, rather, encourage and model how to deal with it? In one workshop, I had separate staff members from the

same agency make polar opposite statements about their agency's policy: one that the policy was that they were not supposed to get too close or to cry when someone passed, and another said, "I've been told it is perfectly ok."

Who has known someone over time? For adults with intellectual and developmental disabilities, it is far too often us, professionals. Can professionals be friends? In these workshops and ones on community building, or person-centered planning, the question would often be: "Who are their friends?" Staff would say, "We are." And then I would put on my theoretical community building hat and correct them to say, "No, we cannot be." Or use the comment to help people realize the scarcity of friendships in people's lives. The question I should have asked myself is whether or not I had just invalidated their only language, the common vernacular, for a close relationship.

Too often we professionals also try to correct people with disabilities and say, "I cannot be your friend," a professional creed that comes out of the history of psychology, psychiatry, and therapy. But who gets to make that judgment? *To deny that perception of friendship is to use the inherent imbalance in power in professional relationships to say that the assessment, or that claim of friendship, is only the right of the professional.* I think we can call that unjust. If we tell someone we cannot be considered their friend, what do we offer in return? That is another reason for including community building in everyone's role, and, by that, I do not mean referral. Trace Haythorn made the very insightful comment in this morning's plenary about the "professional as friend" question, noting (my paraphrase) that professionals are negotiating boundaries all of the time, and to draw such a hard line may keep us from being as good a professional as we can be in a variety of situations.

Thus, until people get included earlier in their lives and more often, we professionals cannot make up for the lack of community and relationships over time, but we need to be honest and say we have been and are a significant part of many people's lives. The questions of aging, "What difference have I made?" and "To whom have I been a blessing?" lead to a second more important reason to deal more creatively with professional boundaries. *Who have "they" made a difference to? Well, you and me, of course.* Honesty demands that we recognize that we professionals are not just the givers and the client the consumer, or the one

being supported, the receivers. We hopefully work in our respective professional roles in this field because doing so fulfills something deep within us, something or someone that touched us, called us, and/or hooked us. Each of us, in our relationships with people with intellectual and developmental disabilities, has had multiple moments of learning, growth, discovery, accomplishment, fulfilment, revelation, and, indeed, joy and celebration. Call them what you will. Those moments both reward our work and compel us forward, in spite of, or maybe because of, the problems faced in supporting people with intellectual and developmental disabilities and their families. Our professional journeys have been a place to discover and use our own gifts just as we seek to help others find theirs. "They" have been our teachers about coming to terms with limits and vulnerability. Those relationships have been the place where, as pastor and writer Frederick Buechner so eloquently phrased it, our calling is experienced as "the place where your deep gladness and the world's deep hunger meet" (Buechner, 2003).

Thus, as the people we support and have known over the years move toward the end of their lives, do we have the courage and honesty to say, "Thank you for the difference you have made, not only in the lives of others, but in mine?" In fact, there is no real reason for that to wait until the sunset of someone's life. Can we not acknowledge the gifts that the people whom we support have given us, and that we have been receivers as well as givers? From my perspective, it is an honor to be welcomed into someone's life and to gain someone's trust, and even more so to be forgiven for the professional limits and mistakes I have made, sometimes repetitively, until I have gotten it right.

In a word, can we move our conception of the professional role towards one of mutuality rather than its inherent, system-built dominance? We do that first by starting three feet in front of us, with the people we have known well and who know us well.

### **Operationalizing and Sustaining Mutuality**

Then, second, how might we operationalize mutuality and help sustain it, over time. Dream with me and fill in your own blanks.

*First, we need to work as hard as we can to discover and sustain any long-term relationships that*

people have had when they come into the orbit of our services and support. That means the direct opposite of what I found when in my first “real” job as Protestant Chaplain of Newark State School in upstate New York, where an orientation booklet for families literally said, “When you drop your child off, don’t come back for six months.” Our system has, for years, strongly affirmed that community means “location, location, location.” I would submit that beyond that mantra is one that should be “relationship, relationship, relationship.” How do the people we support answer the good ol’ Southern question, “Who are your people?” Part of identity is built on who you are as an individual. The other part, just as significant, is “Whose you are?”

*Second, we do whatever we can to minimize the turnover rate.* Career paths, higher wages, better supervision, and recognizing and nurturing the motivation that so many have to put their lives into this area of care and service should probably be the highest priority. It is a matter of social justice and moral righteousness. We cannot ask a society to value the lives of people with intellectual and developmental disabilities if we cannot use recognized social forms of valuing the lives of the people who work and walk with them. I have forgotten the source, but the most poignant way of making this point is that the further away one moves from direct care, the more money you make, or, conversely, the closer one gets to hands-on care, the less.

*Third, we can be more imaginative when professional staff do leave.* When I was a chaplain at both of the two institutions that started my professional journey, I would sometimes hear management complain about the fact that this or that direct care staff person had a relationship with in their unit that made that person “a star.” The professional creed being followed was one about equity of care. The moral question, however, is about the particularity, and mutuality, of love. I used to say, sometimes, “God, I wish everyone here was a star at least in one person’s eyes and care.” Those intense and “special” relationships still happen. However, most agencies say, when someone leaves, “you cannot have contact with the people you supported.”

Why not? I am not sure, but I can think of two primary reasons: First, “Don’t promise something you won’t keep.” However, in other learning environments, where the power is reversed, most

of us would be offended to the core if our favorite professors or teachers had told us that “they could not see or communicate with us after we left.” The pastor of the church I attended in high school once noted a transformative comment made to him by a college counselor: “Keep in touch. What happens to you makes a difference to me.”

The second rationale is not so sensible. “If you are around, it will get in the way of the consumer having to learn to trust someone else,” with the undertone of “listen to someone else.”

So what can we do? The most creative example and strategy I have heard is from Heritage Christian Homes in Rochester, New York, which has developed and nurtured an alumni club for staff. Last I knew, they still worked at making sure people did not promise to be in touch if they did not mean to follow up, but being a staff alumni member was a socially valorized way of doing so. And think of what a difference the simple acts of birthday and holiday cards, and an occasional call, would make in the lives of so many people we support and serve, and in the lives of those who once cared for and with them in a professional role.

*Fourth, to marry the two ideas of community building and sustaining caring relationships, what would happen if the expectation for all professional roles in an agency was that everyone, no matter what role, would do something with one of the people supported by their agency, someone perhaps with the same passions, someone they may have been drawn to for reasons they do not understand...do something with them in at least one concrete way, once a month.* The priority should be people who do not have community connections and friendships. Deep friendships might happen—they cannot be forced, but I guarantee you people would discover qualities that might help in connecting their star with others. A shared cup of coffee, a visit to a favorite community place, some time with no organizational agenda other than a shared relationship.

Who do we consider as our friends? Not the Facebook definition. They are people we may not see for a long while, but they are people whose orbits occasionally and sometimes intentionally circle back into ours from time to time, and the relationship picks up where it left off.

## Reframing Professional

If real community connections, friendships, and long-term relationships are some of the most

important ways to enhance the quality of life of the people we support, their families, and our own, I want to be clear that I am not just talking about the “practice leg” of the three-legged AAIDD stool. I think the same challenges and opportunities are there for those who focus on policy and on research, and the same potential benefits. Many of us move between those three worlds, sometimes every hour. We have seen strides by policy makers in these directions by working hard to ensure the real voices and presence of people with intellectual and developmental disabilities and their families are at the tables. The two adages of “Nothing about without me” and “If you are not at the table, you are on the menu” both have real truth to them. In fact, many of us know that self-advocates and families are the most effective voices. Their stories, more so than studies of prevalence and analysis of needs, will trump data almost any time, unless we can help people see that each person counted in that data has their own story. There are, likewise, creative researchers who are working along with people with intellectual and developmental disabilities as research partners, not subjects, and, I would bet, research begun because of relationships with particular people, and relationships that continue after the project is over. No, every training, research, and policy organization could intentionally practice “each one take one—three feet in front of me” in the same way.

How, then, might these needs and visions of possible professional responses then reframe our basic understanding of “professional.” You know where the word came from: the ancient practice of “professing” vows, first to a religious order, and then later to a guild of practice. The profession of vows was not just an important act of commitment and initiation for the “profess-or,” but it also served as a clear sign and symbol of the person’s values and loyalty. In a medieval era where allegiances switched daily between competing rulers vying for power, gain, and dominance, the profession of vows ideally said, loud and clear: my loyalty is to my God or order, my vow of poverty means I am not out to fleece you, and my vow of chastity that I am not going to take advantage of the potential closeness of our relationship. **There is no denial that this was not always the case**, but, in theory, the values were crystal clear and in that relationship, the seeker could be safe.

We, on the other hand, have dealt with a professional image that says we are to be “value free” rather than “value clear.” If any arena of human

service needs a clarity of values, it is ours, because every professional role in this arena is with someone often on the social margins and one in which the power imbalance is always present. There are times when there are real questions of where our loyalties lie, and which masters we are following. Living out those values is a matter of justice and of making a moral and prophetic statement.

Now, lest you think I am suggesting the modern professionals also make vows of loyalty, poverty, and chastity, I am not. Two of the sacrifices we could make, however, are the ones of “distance” and power. But the question remains, in what ways can we be crystal clear that we are committed to not abusing our power and “their” trust, both of which, we cannot deny, have not always been the case. Let me suggest several possibilities, including a renewed commitment to community building and sustaining long-term relationships, starting three feet in front of us.

First, as professionals, we are to listen deeply. That is not easy. One might say that there are multiple examples of evidence-based practice in which listening deeply is not standard practice. We don’t have time: we are fixers, doers, prescribers, plan makers, standards compliers, schedule fulfillers, paper pushers, deadline reporters, grant seekers, policy advocates or makers, dogma defenders, and, in the midst of that, just as competitive as we like to say and think we are collaborative. To listen deeply, to receive another, to hold space for them, is to risk having our own truths challenged, and new claims on who we are as people and professionals. I once heard Parker Palmer say that one of the reasons we resist listening deeply to another and their truth is that we are afraid of where that truth might call us, and how it might change us. But both individuals with intellectual and developmental disabilities and their families need to feel that safety, a safety that far too often is endangered by professional prescriptions and dogma of one kind or another.

Second, can we as professionals become as comfortable with paradoxes as we are with outcomes and certainties? One paradox is that *being with* people is as important as *doing for* people. A second, perhaps hidden in plain sight in this talk, is that our whole system of services is built around saying, “come to us, we can help.” But, to build community, we have to learn how to give away what we know so all kinds of others can recognize their capacity to help as well. We do that



professionally in talks, journals, and teaching, but do we do that personally in helping people connect in our communities? Could we, three feet in front of us, help answer the questions that communities are asking? A third paradox, especially in community building, is that to be a professional is to know what we don't know, so that we are willing to ask others and learn from them. Or, in other words, I have to learn how to professionally use my ignorance. Fourth, as the 1951 *Treasury of Humorous Quotations* (Esar & Bentley) quoted George Bernard Shaw as noting, there is the paradox that America and the United Kingdom "are two countries separated by a common language." Being professionals and community builders means being fluent in at least two languages, that of our disciples and systems, and that of community. One involves data, plans, policy, goals, outcomes, and "evidence-based practice." The other is stories, art, symbols, pictures, shared meals, music, and songs.

Third, we need some new models of professional training and education, ones that are not so much new as they are old. Professing vows in an order, or, in a guild of workmanship and practice, was seen not just as the acquiring of knowledge and skills in the evidence-based practices of the time, but as formation of character and commitment. Formation of character and commitment recognizes that "listening deeply," "sitting next to," and "walking closely" are all going to lead to places that touch you way down, experiences that shatter illusions, and where you need to know how it is that your person, with its strengths and weaknesses, both impacts and is impacted by your professional experience. Mentors, role models, and heroes are some of the ways we talk about those who have helped us in this kind of learning. Can we not say to those whom we have served, "Thank you for mentoring me." We are also beginning to understand the value of commitment, not to an order, but to a community of practice, where we can learn anew, and be challenged, personally and professionally. Formation gets back to thinking about "What drew you in?," "Who and what called you?," and "Where does your passion and vision come from? How do you and we sustain it?" If we don't do that, we continue to run a system that has no idea how to build and maintain commitment, and then falls back on compliance (Gaventa, 2008).

Fourth, we need to recover, or re-member the gifts in our professional work and lives. "Re-hyphen-member," make them part of us again.

Not simply focusing on the gifts and strengths of the people we support and serve, nor being able to recognize and name our own. No, I mean remembering the gifts of what we have received in our work from the people with whom we journey and the cause for which we strive. What has this meant to you? To me? At the guts of who we are. Then use those guts to say "thank you" for what others have taught and brought to us long before someone is aging out in the ways all of us do. Parker Palmer (1998) captures some of this in the very title of his book, *The Courage to Teach: Recovering the Inner Landscape of a Teacher's Life*. Be honest about the mutuality of the giving and receiving, and be willing to act on that sense of giftedness in friendship, advocacy, building connections, and sticking to some relationships over the long haul.

No one has ever done that better in my experience than Nick Hadju, a direct support professional (DSP) who spoke at a one-day workshop I helped organized before the Alliance for Full Participation conference in 2005 in Washington, DC. The day was on building bridges between secular and faith based services. We asked Sue Swenson to be one of the speakers. She in turn said, "Can I let a couple of the direct support professionals who work with my son, Charlie, at Jubilee, Inc., speak in my stead about the integration of their faith and professional lives?" The second speaker, Nick, stood up and said, "I am not a very good speaker, so I wrote a poem." As he read it, the room got quieter and quieter. It was one of those moments when you knew you were on holy ground. You may have seen it already. With his permission, it has been used widely.

#### My Friend Charlie

He is my friend: I am his friend  
I help him out: He helps me to learn  
I help him to learn: He helps me to grow  
I help him to grow: He teaches me to accept

His struggle: Is my struggle  
His vulnerability: Leads to my respect  
My respect: Leads him to trust  
His trust: Leads to my devotion

His availability: Feeds my desire to be needed  
I keep his secrets: He keeps mine  
We have an arrangement

His lack of self-consciousness: Leads to my tolerance  
His constant need for stimulation: Leads to my patience  
His discomfort: Sharpens my sensitivity  
His unhappiness: Is my challenge  
His presence: Eases my isolation  
His loyalty: Leads to my loyalty  
Which leads to mutual appreciation

His brokenness: Makes me accept my own brokenness  
Which leads to healing  
His humanity: Leads to personal connection  
His steadfastness: Centers me

His smile: Is my reward  
His joy: Lifts my spirits  
His happiness: Gives me a sense of purpose  
His struggles: Expose my anxieties  
Which tests me  
Then strengthens me  
And in turn bolsters my faith

In guiding: I am guided  
In helping: I am helped  
In teaching: I am taught

In his laughter: There is joy  
In that joy: There is energy  
In that energy: There is spirit  
In that spirit: There is grace

In his eyes: There is a glow  
In that glow: Is his soul  
In his soul: There is God  
And in God: There is peace.

(Hajdu, 2005. Used with permission.)

### Re-Membering the Gifts of Professional

Recovering, re-membering what it means to be professional. It may be one way individuals and families may come to feel not so alone. But we will be much better teachers, because everyone around us will learn from our behaviors, from seeing us doing what we say and practicing what we preach—three feet in front of us.

In one of Bob Perske's (1972) first writings about pastoral counseling of families, he tells a story of one father saying to another, "People don't know

they are a tragedy unless we tell them." The reverse of that may be true as well: People don't know they are a gift unless we recognize it and say so.

We have many motives for coming to AAIDD and for being committed to this organization. At our heart, we are about knowledge lived out in practice. We also come to share our gifts, not only to help and learn, but also because there is part of all of us that wants to be well known. You may not know that the biblical Hebrew word for "knowing" was about much more than objective knowledge. It also connoted intimacy and relationship. It took me a while, as a missionary kid reading the King James Bible, to realize that when Noah went in and "knew" his daughter, it was something he should not have done. Robert Raines (1976), a clergyman and writer, authored one of my favorite quotes: "We think we want to be well known when what we all really want is to be known well." One is reminded of the opposite of this by Michael Smull's observations that, too often, people with multiple disabilities become known as "people with severe reputations" (Smull & Harrison, 1992).

As professionals in the lives of people with intellectual and developmental disabilities and their families, we are privileged to know others well. Many have trusted us, and helped us know ourselves better. Perhaps we can do better at being known well to them, as companion, advocate, neighbor, synagogue member, guide, connector, Braves fan, and even friend...so that maybe long before their ends, or ours, and certainly by then, we can say to the ones with whom we have travelled, "You have blessed me, just as much so, if not more, than you say I have blessed you." Re-member the gifts of what it means to be professional.

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