

## Honor the Past. Then Get Over It.

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### Abstract

This speech was presented at a conference, the National Goals in Research, Policy, and Practice, held in Washington, DC, on August 6-7, 2015. The conference was a working meeting to summarize the current state of knowledge and identify a platform of national goals in research, practice, and policy in intellectual and developmental disabilities. The meeting was jointly organized by the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota; Rehabilitation Research and Training Center on Developmental Disabilities and Health, Institute on Disability and Human Development, University of Illinois Chicago; Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities, Institute for Community Inclusion, University of Massachusetts Boston; The Arc of the United States; Association of University Centers on Disabilities (AUCD); and American Association on Intellectual and Developmental Disabilities (AAIDD), with the support of National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

**Key Words:** *research goals; intellectual disability; developmental disability; big ideas; evidence base*

I have two assignments this morning. One is to talk about our progress since the last Research Goals conference in 2003. Some predictions came true, some were close, many were missed entirely. The intellectual and developmental disabilities (IDD) community disagreed about which fundamental questions to ask, they agreed on some consensus statements that turned out to be right on the money or were at times too cautious, or too ambitious, or just wrong. We anticipated the new focus on transition. We saw the likelihood of an economic downturn—though we missed the scale of it. We saw new workforce concerns and anticipated the difficult impact of higher standards in schools. We saw the expanding focus on self-determination, and we acknowledged the family stress that comes with home-based supports.

Some things we didn't see. We didn't see this President. We didn't imagine the Affordable Care Act. We didn't quite think we would get to a place where we could talk about how race affects special education and human services—perhaps we are not quite there even now, though we have better data than we did then. We didn't imagine the energy and focus this administration would bring to issues that affect us directly. We didn't see the finalization

of the international treaty called the Convention on the Rights of Persons With Disabilities, nor did we know that much of the work of constructing that treaty would be carried out by organizations of and for people with IDD. We did not foresee that one advocate, working for a homeschool association, would stop it in its tracks in the Senate by making up wild tales that it would threaten our national sovereignty. We didn't envision that one person could keep us out of the international community that continues to work to advance this understanding of our existing human rights, nor do most of us know that the children's treaty and the women's treaty were also stopped by this same single storyteller.

I urge you to be committed in your work here. We need to find ways to move forward. I hope to offer some assurance that you cannot be wrong in what you do together here—it is inquiry, it is addressing what is possible, and making new possibilities. You are plowing new fields and if you unearth boulders, you will have to figure out what to do with them. You may decide to just plow around them and leave them for the next research goals conference. It would not be the first time an important thought has been put aside for later.

My other assignment is to leave you with some big ideas, bold thoughts, and new connections to guide your work for the next 2 days with your colleagues. Think through how we might solve some of the biggest problems and some of the newest problems experienced by people with IDD and their families. This assignment I accept eagerly. You are here because you want to make a difference. You are primed to think big and for you it will be like falling off a log. I am not a researcher, but I am an optimist.

There are five key points I want to make:

1. Nobody knows what research is. Or everybody knows.
2. Often, research has its foundations in values and moral commitments, but this doesn't mean it is "soft."
3. Powerful science is expressed in stories, which are not science.
4. Evidence is our guide. Except when it is not.
5. Research is a foundation of policy, and it is not.

Let me begin in the fifth century BC with Plato. Plato was the butt of jokes in the Academy out in the manicured forests outside of Athens because he bothered to record the conversations Socrates had with ordinary people. These conversations involved practical questions like "how to live," "how to ask questions," and "what is society?" The Academy labeled Socrates' work as *exoteric*—outside of the circle—because he spoke to people who were not of the Academy. They thought the important research was what they were doing, talking among themselves. The Academy thought their work was important because it was *esoteric*—that is, "inside the circle." Sound familiar? We sometimes call this esoteric space the *ivory tower*. Now, to some extent, this ended well for Socrates, in that the Socratic dialogues survived to become the foundation of modern thought, and his name and his method of inquiry are mentioned and followed today. Whatever they were talking about inside the circle, back in the woods, among themselves, esoterically—well, that has disappeared. Did you know Socrates resisted Plato's recording of the dialogues because reading them would cause students to be focused too much on the past—too *paleoteric*—and would cause them to lose their ability to memorize what was spoken and create new topics and new ideas—to lose what was *neoteric*? We

are here today to be neoteric. We are here to draw new circles, not just to decide who is "in" and who is "out." We are here to find new ways to think about our common problems. Ignore for now the fact that things didn't end well for Socrates.

Aristotle, a student of Plato and recognized as the progenitor of the scientific method, took these distinctions in a different direction and distinguished three kinds of investigations. In his *Metaphysics* he distinguished between theoretic, practical, and productive (or poetic) research. I think you live in this space between the Aristotelian distinctions as researchers in IDD. Your research encompasses the theoretic: mind, education, biology, communication even as you try to make our habits and practices better (practical), and as you try to help people build systems, organizations, services, and technologies (productive).

Kant agreed with this distinction of Aristotle by building his three Critiques to address the theoretic, practical, and aesthetic: The Critique of Pure Reason, the Critique of Practical Reason, and the Critique of Judgment. Kant wrote a little book that few today read called *The Conflict of the Faculties*. He argued that the university department (or faculty) that works closest to the practical realities of human life is the most important faculty and their research should be given the greatest support and honor. Lest you think Kant was some wishy-washy philosopher who said this because he liked "soft" research, he was a physicist and on the physics faculty as he made this pronouncement. Do you think your Deans understand this, that your work is most honorable because it concerns the struggles of ordinary people? Our work encompasses the importance of aesthetics as well—what Kant called *judgment*. We use aesthetics all the time to judge good from bad. We can and do tell by the smell, by the look, by the sound, by the results, whether a residence is a home, or whether a workplace is community-based, or whether a classroom is a school.

Our 2003 Goals report included a biomedical sciences section, because we expected great movement in that sector—and we have seen it. Perhaps we included it then because we still believed in the white coat of *real* research. Our field has evolved from a foundation in biomedical sciences while our methods of approaching disability have expanded beyond a *medical model*. These white coat discoveries may yet change the world, but let's also remember that the more powerful new discoveries

are, the more they create new tensions and new ethical issues that will be resolved in social discourse and by other disciplines.

So what is research? Must it be esoteric? While participatory action research can be real as well as rigorous, we still defer to the doctor in the white coat as having a superior understanding of research. Snap out of it. In the decade of the fifties and sixties, we thought IDD would be “defeated” by medicine and surgery and other treatments. Our first university centers were funded in medical schools. They did—and do—good work. We can honor it, and yet move beyond it: it is only a part of the larger body of research that matters. We don’t need to abandon medical research as much as we need to master it—and this is harder than it sounds. For example, some physicians still believe that their relationship with a child’s parents allows them to perform unspeakable surgeries on a child if the child is disabled. As if the disabled child has no dignity of person. Consider all the work done around growth attenuation, commonly called the Ashley treatment. Here you will see medical science, accurate and precise, in service to notions of humanity and disability that are woefully unexamined and out of date. We must honor our medical past, and get over it by helping those who practice it see our new fundamental understandings.

In 2003, we included sections on accommodations, as we do today. In 2003, we were prescient in our focus on the importance of computer and electronic technology and the need to invest in new strands of research to guide its development. We focused on family support and accommodations in everyday living, reflecting our field’s evolution towards a rehabilitation/accommodation approach to disability beyond the purely medical framework. New perspectives suggest that full accommodation of students with intellectual disabilities should cause us to question whether “intellectual disability” exists at all. (Harvard Education Letter, Kliwer, Biklen, Petersen March 25, 2015, “The End of Intellectual Disability.”) So, yes, we must honor those who helped us distinguish intellectual disability from other mental impairments even as we strive to get over it by expanding our understanding of how accommodations might work, or might redefine the fundamentals for us.

In looking further back than 2003, I note a key fact: Most of the research in our field seems to

have roots in moral and not in basic scientific discoveries. These moral discoveries are research, too. Burton Blatt’s photographic documentation of conditions in Christmas in Purgatory, and his exploration of the universe of “ordinary” Germans who did nothing during the Holocaust, brought revolution to how we see our fellow humans and how we see ourselves. Wolf Wolfensberger’s and others’ assertion of the theory of normalization was as revolutionary for us as Galileo’s assertions. Gunnar Dybwad asserted that we misunderstood intellectual disability by assigning mental ages from which people could never escape, he focused on building international structures that would help us know what is universal in our experience, and he advocated for bringing children with disabilities into schools rather than focusing only on closing the institutions, because he believed the one would follow the other. He asserted, too, that organizations would be on a razor’s edge if they tried to be providers and advocates at the same time. In many ways, we are still testing his moral assertions. Bengt Nirje found the connection between the philosophical commitments the world made after the end of the Second World War and the simple choices parents made about how their children with disabilities would be raised and loved in the plains of the American North. David Braddock understood that a longitudinal display of visual information would help us see our States and our nation, and the choices we make about aiding vulnerable citizens, in undeniable relief, a history that we can examine even as it unfolds. Deborah Spitalnik protects and advances the legacy of Elizabeth Boggs, a legacy of effort, knowledge, organization, and political action that has been unmatched in the modern world even as it is an inspiration to generations of mothers and fathers who see that the world must be changed, that somebody’s got to do it, that it’s a darn shame, but it must be us. These people are researchers all, and searchers, too. Of course, there are hundreds of you. The facts that you uncover are not always *scientific* facts, but they are facts nonetheless. Here is where to honor the past requires some reading. Go to AAIDD’s website and get the collected papers of Blatt or speeches of Dybwad, look for other hidden gems, talk to the people who are still with us, honor their struggle to assert the moral facts as they saw them. Then get over it. Find your own new moral facts. The expression of what is right often changes with the

times as our society and its institutions change, even if the fundamental human realities stay the same. The expression of what is a right changes now that we have social media. I think there is plenty of evidence that the next big research agendas in our field will come not from a mouse model or a statistical analysis, but from a new expression of what is right.

From the Developmental Disabilities Act, the Rehabilitation Act, IDEA, and the ADA we have evolved towards a belief that without discrimination we are all capable of anything. We assert that everyone can work, that everyone can live independently, that everyone can be in charge of their own life, and in so doing we lay out new avenues of inquiry.

Questions are coded into our American DNA. We seek new ways to understand, we commit ourselves to rational approaches, we believe in evidence-based practice (and I, for one, believe in practice-based evidence). Sometimes we must fight to maintain that rationality in the face of media that do not know what to make of science, and science that hasn't yet learned how to tell a story through the media. We know that citizens sometimes do not understand the limits of science. They do not know that statistics means never having to say you're certain. They do not know that the plural of anecdote is not data. They think truths are universal, and that if too many carbs are bad for you, then zero carbs must be great for you, or if a little applied behavior analysis (ABA) is good for a child, then round-the-clock ABA must be great, or if massive quantities of mercury are bad then using a vaccine that *used to* contain mercury must be a threat. Don't get me started on vaccinations. People who make bad decisions often do so in the name of science and rationality. We muddle through. We are not seeking a unified theory of life and disability at this meeting, we are seeking some answers and some new ideas. More than two or three generations back, we had nothing—so pay attention, and document what you think. You are part of a revolution.

Perhaps you know that history, like life, is lived forwards and understood backwards. Most people don't know that Thomas Jefferson had a sister, Elizabeth, who was 2 years younger than he and whom he loved dearly. According to his personal diaries at Monticello, he turned away from politics after his mother died because he was

caring for Elizabeth, who was described by a neighbor as being intellectually disabled. Perhaps we would say she had anxiety disorders, or autism, too. There was an earthquake and aftershocks at Monticello in 1774 during a period of heavy storms, and Elizabeth was so distraught that she ran out into the storms and was drowned in a nearby river along with the maid who was trying to save her. So in 1774 Jefferson returned to political work.

We have very few historical facts to go by as we understand Elizabeth Jefferson and her parents' and sibling's commitment to her support. We do know that there were already institutions in the United States in those days—madhouses, really – and that Elizabeth's family chose to keep her at home. Incidentally, Patrick Henry also chose to keep a disabled family member at home, rejecting the madhouse and building a basement apartment for the care of his wife after she suffered what appears to be a serious mental illness. (NB The homeschooler who stands in opposition to the CRPD claims to take his inspiration from Patrick Henry.)

I believe that when Jefferson wrote “We hold these truths to be self-evident, that all [people] are created equal, that they are endowed by their Creator with certain inalienable Rights, that among these are Life, Liberty, and the pursuit of Happiness,” he was including his sister Elizabeth, and our sisters and brothers, our sons and daughters, our self-advocates, in the goals of our nation. Jefferson wrote the words that became the basis for the 14<sup>th</sup> Amendment, for the Equal Protection Clause, The IDEA, The ADA, for all of the work you have done together over the years on behalf of and with people with disabilities. I doubt that he saw where it would go, but I am sure he knew that it would go. Inscribed on the walls of the Jefferson Memorial is an edited version of this paragraph:

I am certainly not an advocate for frequent and untried changes in laws and constitutions. I think moderate imperfections had better be borne with; because, when once known, we accommodate ourselves to them, and find practical means of correcting their ill effects. But I know also, that laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new

discoveries are made, new truths disclosed, and manners and opinions change with the change of circumstances, institutions must advance also, and keep pace with the times. We might as well require a man to wear still the coat which fitted him when a boy, as civilized society to remain ever under the regimen of their barbarous ancestors. (Jefferson to H. Tompkinson [AKA Samuel Kercheval], July 12, 1816[10])

You can do no better than to take these words as your charge for the day. Honor our past, our leaders, the men and women whose research and assertions brought us to where we are. Then get over it. It will dawn on us that they are our barbarous ancestors, as we ourselves will be soon enough. That is the real outcome of research: Not certainty, but progress.

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*The author wrote this commentary outside of the scope of her employment with the U.S. Department of Education. The contents of this publication do not necessarily reflect the views or policies of the U.S. Department of Education.*

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