

***Remarks by Deborah M. Spitalnik, PhD
on Receiving the AUCD Lifetime Achievement Award***

*Association of University Centers on Disabilities Annual Meeting
Washington, DC
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Beloved colleagues- thank you.

I am so moved and appreciative of this recognition. What I am most grateful for is the life of meaning that this network has given me. When I wrote these remarks last week, I could not have anticipated the through line with yesterday's opening plenary of Emerging leaders and Kiran Singh Sirah's Keynote.

I have a decades long love affair with the DD Act— the poetry of our work— a vision of our collective humanity.

Galvanized by the advocacy of people with disabilities and families, the people in this room and our predecessors have created so much progress in our field. As we listen harder and more concertedly to people with disabilities and families, we have learned more. We have created better supports, and interventions. As Maya Angelou reminds us, "I did then what I knew how to do. Now that I know better, I do better." Opportunities have increased but so has complexity. Gaps persist between our shared ideals and the reality of life for many people with disabilities, their families, and communities.

As a doctoral student in 1974, I attended a conference at Kennedy-Krieger where Paul Friedman, then head of what is now the Bazelon Center, spoke. When I heard "disability is a civil rights issue" I knew that I was home.

Dr. Pearl Primus, dancer and anthropologist, spoke of her life as a river, taking many turns, but always flowing forward. My adult life has flowed, been supported, and carried forward by this network. As an MCH Fellow before it was called LEND, at St. Christopher's Hospital for Children in Philadelphia, a trainee at Temple when it was a UAF, and then as a staff member there, starting the first community programs in the network. What a privilege and a gift to have been entrusted to start a UCEDD in New Jersey.

At the heart of the flow of my life is my husband John Weingart— his love, patience, steadfast support, and humor makes all things possible. Our beautiful daughter Molly, the center of our world, teaches me with grace,

humor, and persistence about the challenge of living with invisible disabilities. These threads converge to a collective imperative that we must weave together the fabric of life to create a world where everyone is welcomed, nurtured, supported, and belongs.

The idea of lifetime achievement raises the generational threads that bring us together as a network. The Boggs Center, begun in 1982 as UAF—University Affiliated Facility, was considered a “second generation program” because we were deeply embedded in the New Jersey community and partnered with the state. We became a LEND program in 2016 as a community networked program, made possible by the expansion of the Autism CARES Act.

The Maternal and Child Health Bureau reminds us of the power of lifelong connections- those in this room and with our predecessors. I am continually learning from the individuals and families for whom we work and feel a powerful sense of mutuality that erases labels and roles- for that I am enduringly grateful.

As educators we get to experience the generativity inherent in contributing to others’ development. Mentorship is a through line, a heart line that embraces us and binds us one to the other. Being mentored is a gift and much of my path rests upon the kindness, wisdom, and mentorship of Dr. John Bartram, an early and unsung father of Developmental and Behavioral Pediatrics, Elizabeth Boggs, Gunnar and Rosemary Dybwad, Dr. Larry Taft, and Sue Swenson.

From being mentored there is a mutuality in the privilege of being a mentor. My joy and gratitude to many dear ones who are here and far flung. What could be a greater gift than to see our students and colleagues develop their skills and apply expand their compassion toward the unending challenges of supporting full lives in welcoming communities.

We all must be continuing to expand our circle of empathy.

I think about and feel deeply about kindness, love, and trust. Phillip Alberti at the Association of American Medical Colleges reminds us that trusting relationships are essential for health equity. For each of us and all of us, relationships are at the heart of our work. As I delight in the friends and colleagues who are here tonight, I am convinced that the essence of our efforts must be to contribute to the circumstances that support people with disabilities to have the opportunities for the connection and caring we all hold dear.

As UCEDD and LEND leadership, we are always aware that the excellence of our work can only flower if we have created the types of trusting relationships

that make our work visible, supported, and able to continue. I contend that there must be a unique algorithm in the LifeCourse of Center directors. An algorithm of the number of department chairs times the number of deans times the number of State DD Directors times the number of state agencies times the number of AIDD/ACL commissioners squared.

Our mandate is essential, our cause is just, and we are called upon repeatedly and continually to build relationships, where change is the only constant.

My first Directors' meeting, when the network was AAUAP, there were three women in the room, no one of color, and no one with a disability. Several decades ago, as more non-physicians became directors, there was not universal embrace and warmth extended. It is only right that we have become more embracing, but we need to do more and be more.

As individuals and collectively we must continue to wrestle with the query: who is outside of our embrace? Who because they do not communicate in a traditional spoken voice? Who because of race, language spoken, immigration status, or being part of an under-represented community? Who because they are further disenfranchised across the digital divide?

We are called, Toni Morrison reminds us "if you have some power then your job is to empower someone else."

Our mandates to discover, learn, educate, and inform are essential in bending the arc towards justice. In this bitterly divided society and aching world, let us heed the imperative of the late beloved Bobby Silverstein: "the disability community must stay together." What we hold dear and essential to all our lives and especially for people with disabilities: Social Security, health care, reproductive health, mental health, Medicaid, food assistance and housing, I fear will be threatened in ways that go beyond past assaults and anything we might imagine. As always, and especially in these times, we have an ethical responsibility to create hope, to act with optimism, and to be steadfast with love, kindness, and courage.

With my deepest thanks, I leave you with the words of Amanda Gorman:

*"For there is always light,
if only we're brave enough to see it
if only we're brave enough to be it."*

Thank you, dear friends, colleagues, and AUCD for this evening, this award, and the gift of my life.