



RUTGERS HEALTH

The Boggs Center
on Disability and Human Development

Robert Wood Johnson Medical School

Department of Pediatrics
Robert Wood Johnson Medical School
Rutgers, The State University of New Jersey
Liberty Plaza, 335 George Street
New Brunswick, NJ 08901

boggscenter.rwjms.rutgers.edu

p. 732-235-9300
f. 732-235-9330

Deborah M. Spitalnik, PhD Retirement Remarks September 4, 2024

Thank you all for being here this evening.

I am overwhelmed by the love and kindness in this room.

Thank you for the life of meaning you and this community have given me.

It is my heartfelt conviction that the essence of our efforts must always be to contribute to the circumstances that support people with disabilities to have opportunities for the connection and caring we all hold dear and which I feel so deeply from all of you tonight and over the last four decades. I am so grateful.

John & Molly-the first Boggs Center baby. They are my heart-my center- the blessings of my life.

The ethos of my parents Hannah and Moses Spitalnik was we all bear responsibility to and for each other. As Marian Wright Edelman the founder of the Children's Defense Fund, has expressed "service is the rent we pay for living".

From my mother a first generation American, Molly's beloved grandmother "Peapie", there is a throughline from her parents- my grandparents, from their Eastern European village- the "shtetl". The throughline- a heartline is community: that life is with people and life is about people. This heartline is the common good. "Living for others is a rule of nature. We are all born to help each other". The words of Pope Francis remind us that the best of all our traditions and backgrounds share this commitment to the common good.

We come to this endeavor for myriad reasons. Some through our own disabilities were born into this; some because our children or sisters and brothers bring us here. Some from a sense of social justice and others through education or work or serendipity. Whatever our path, we are bound together in the imperative and privilege of working for the common good: the collective enterprise of "tikkun olom- Hebrew for "healing the world".

In 1981 the felt need in New Jersey for innovation on behalf of people with disabilities was the genesis for planning the University Affiliated Facility- what is now The Boggs Center on Disability and Human Development. Four decades later I continue to be grateful and still somewhat incredulous that Dr. Larry

*New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service
New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program*

Taft- the first chair of Pediatrics at Robert Wood Johnson Medical School, Dr. Elizabeth Monroe Boggs, the DD Council, and especially Eddie Moore entrusted me with the responsibility to start The Boggs Center.

When The Boggs Center formally began in 1983, 5,942 of our fellow New Jerseyans lived in “state schools and hospitals”- large crowded segregated state institutions. 945 children lived there, many who had been placed in the nursery at birth never having lived in the shelter, comfort, and embrace of their family home. Group homes had recently begun, and Early Intervention was just beginning. Our beloved Matt Byra and other children with significant disabilities went to segregated Day Training programs, not administered or connected to the Department of Education or any local education agency and away from where their sisters and brothers went to school. The Children’s System of Care didn’t exist. What is now the Division of Developmental Disabilities, was then DMR, and eligibility required that people bear the label of mental retardation. Before I came to New Jersey I had worked to close institutions-Pennhurst in Pennsylvania, Laconia in New Hampshire, and Mansfield in Connecticut. I felt then and even more deeply now we are not going back.

Could we have imagined then that employment would be the desired outcome for adults with disabilities? That children with disabilities would have access to the general education curriculum and many emerging adults and their families would be exploring college, as postsecondary education? That the devices we all hold in our hands so many hours of the day could support people who don’t use a spoken voice to communicate? That the prevalence of Autism would have grown so much? That Gus and his family would be leading us as a nation to appreciate the love and gifts we all bring to the common good?

While we can appreciate and celebrate that there are more services and opportunities than ever, there is still much to be done to close the gap between our ideals and what is real. We need to find ways to truly walk alongside people in the way they want to be supported. To find ways to support self-direction and self-determination for all people, that doesn’t require that a family is able to take on additional full time responsibility. Most achingly and poignantly that families as they age can feel comfort and reassurance that their child’s well-being will be assured, even beyond their own lifetime.

Elizabeth Boggs, my intellectual fairy godmother considered Molly the only grandchild she would ever have. Two mothers, Elizabeth of New Jersey, mother of David with intellectual disability and Elsie Heisel of Ohio, mother of Robin with cerebral palsy, were the moving spirits in the construct of developmental

disabilities- a unifying concept of early onset, neurologically based, functional disability with the need for individual coordinated services across the lifespan. In the late 1960s, Elizabeth and Elsie joined forces in advocacy so that the 1970 federal legislation would raise all boats- not create winners and losers. Elizabeth was the architect of the federal DD Act, the vision of our collective enterprise guiding us to support lives of presence, participation, and self-determination in the community. While John has always been my heart, my everything, I do confess to a continuing love affair with the DD Act- the poetry of our field. The DD Act, in the words of Sylvia Plath “speaks to my bones” lifting up “disability as a natural part of the human experience” and creating centers in universities that are a bridge with the community. What a dream date this has been for an inveterate multitasker, first at Temple University and for 41 years at The Boggs Center and Rutgers, to be able to be part of a spirited enterprise, guided by lived experience, educates students, provides supports and care, generates and implements ideas and makes information accessible to the people whom it is about and who need it. It has been a privilege and a pleasure to teach, mentor, write, start programs and work to improve policy.

What a gift to have as colleagues the people of The Boggs Center. Day to day, with their skill and commitment they have made the center a trusted resource. Each and every one of them has made life better for people with disabilities, families, and those who work on their behalf. I make this transition with confidence and excitement about the even brighter future that they will create in the trusting relationships they have with all of you.

I am compelled by the idea of the Life Course- how for all of us our early experiences shape our path in ways cumulative and powerful. For many people with disabilities and others on whom society turns its back this path is not always positive nor easy. For whatever challenges I’ve had in my life or our family I have had such a richness of blessings in my life course. I was a Maternal and Child Health Interdisciplinary fellow at St Christopher’s Hospital for Children in Philadelphia- before that federal program became LEND and I’ve now gotten to teach LEND fellows. I have had the gift of education, of powerful teaching and mentorship, from Abraham Maslow, Ira Goldenberg, Dr John Bartram who was a developmental pediatrician before there was a field and started the first services to children with disabilities in Philadelphia, Dr. Larry Taft, and Dr Elizabeth Boggs. There has been a seamlessness of colleagues becoming friends, mentors and inspiration— many of whom are here tonight— and who have recently written. I have been inspired and sustained by Ellie Byra, and our beloved late Diana Cuthbertson, sister in cancer journey, visionary family educator, and partner in family centered care.

What generative satisfaction and privilege to be able to use what has been so generously given to me and to then teach and mentor others

It is never tiring and always inspiring to be with the NJLEND fellows, with 25 generations of Family Medicine residents and to know that for the last 30+ years and going forward The Boggs Center's Seminar on Family Centered Care and Developmental Disabilities has reached every student at Robert Wood Johnson Medical School. When we hear the 3rd year medical students' thoughts and feelings in a reflective practice session after they have been in the homes where families and their children are the students' educators, I sometimes feel like I'm "a spy in the house of love". The love and power of lived experience. The generosity of families and people with disabilities despite whatever they are carrying, taking time and making space to contribute to the development of future professionals so other people with disabilities and families receive the care they want and need, with respect and heart. It is the same generosity of spirit in how families utilize family support services conscious of the needs of others. The generosity of caring and friendship that families in this community have given to me and my family.

Policy is context and to me context is everything. I came to policy in struggling to understand the feelings of sameness and sadness evoked in me from volunteering at Fernald State school when 3300 people lived there, working at Bellevue Psychiatric Hospital in the heyday of state hospital commitments, and teaching a Kindergarten class of 37 children and with only 34 chairs in the Boston Public Schools, when it took 5 years to have a child tested for developmental concerns.

Policy expresses how we as a society hold each other, what we feel we owe each other and how we distribute or deny justice. More than ever, it is my deeply held belief that unless we act out of love in all endeavors, but especially the human enterprise in which we are joined here, public policy goes awry.

The structure of society emerges more sharply when we are dealing with disability, illness, or other social disadvantages. We become more connected and affected by public policy, taking us out of the realm of our immediate lives, our family, our friends. From the delivery room to the neonatal intensive care unit, from the concerning image on an x-ray, or the unheeded stop sign. The most personal and intimate aspects of life are at risk of becoming impersonal, controlled by others with decisions made a distance from us. The essential challenge for public policy is to allow people to remain in the ordinary and the personal and still get the supports and help they need and desire.

To have had opportunities to work on policy, nationally and especially in New Jersey related to Medicaid and disability has been for me the fulfillment of the promise in Simple Gifts, the Shaker hymn, that “by turning turning we come round right”.

Beyond my personal temperament, I believe that we have an ethical obligation, to proceed with optimism, creating and sustaining hope.

In this deeply divided society, we are called to scaffold hope with vigilance, an obligation familiar to our community, necessitated by our love for the people in our lives.

The vigilance demanded of us begins with the personal but extends to our collective social circumstances and experience, as Thomas Mann describes: “A human being lives out not only his personal life as an individual, but also, consciously or subconsciously the lives of his epoch and his contemporaries”.

The daily and often continuous vigilance families feel for the well-being of their family member- the disrupted or never quite sound sleep listening for signs of distress. The vigilance engendered by the discontinuities in services and systems addressing lifelong disability. How school or other services can change so quickly with the loss of a dedicated direct support professional or teacher or therapist or with personnel shortages or a new policy. The many transitions across life stages and how services and systems are balkanized, including the transition to adult life with which so many are struggling.

Our lives, especially for people with disabilities, are surrounded by the nexus between policy, politics, and government. Our epoch in this bitterly divided society demands of us even greater vigilance than we have ever had to exercise. 50 years ago, as my adult work life was beginning, the 1975 Education of All Handicapped Children federal legislation, now known as IDEA- the Individual with Disabilities Education Act-IDEA- established the legal right to a “Free and Appropriate Public Education”. This constitutional right and the Children’s SSI-Supplemental Security Income are what has made it possible for children to remain in the embrace of their families and our communities. IDEA and a “free and appropriate public education” is a paradigm shift, and most families do not know the world when children with disabilities were not allowed in schools. If we cannot imagine the world without this bedrock for children with disabilities and families, perhaps we should take keener note of how this Supreme Court has abrogated other longstanding rights.

Project 2025 demands extraordinary vigilance from all of us, especially our disability community. Project 2025’s goal is the “dismantling of the

administrative state”. That means the removal of the supports and social institutions, that have made it possible for our disability community to survive and thrive. From a positive start in life through Part C Early intervention through Special Education and the possibility of an adult life in the community of contribution and connection, IDEA is fundamental to the life course. What would become of this and all children with the elimination of the federal Department of Education?

Medicaid is the bedrock of health care for almost 2 million of our fellow New Jerseyans and approximately 40% of our state’s children. Medicaid is the foundation for services for adults with developmental disabilities in New Jersey and across the nation. Medicaid as a life line is explicitly threatened by Project 2025 with block grants and demeaning, ill-founded, erroneous notions of personal responsibility. Unlike previous policy threats, people with disabilities are not held harmless. We must be vigilant in attending to and against these threats: what is being written, what is said, and what is intended and meant.

Eliminating the Affordable Care Act, the 14 year threatening drum beat that yet again is getting louder, could erase the anti-discrimination provisions for people with pre-existing conditions. Most of us in this room and those we love would not be covered by health insurance, further threatened and excluded by annual and life time caps in coverage.

Our epoch demands that to the on-going vigilance that has always been a necessity for the disability community, we exercise renewed vigilance to prevent Project 2025. We are all called to translate our vigilance into action. We are not going back.

The disability rights movement- family advocacy and self-advocacy teaches us lessons of democracy: everyone is valued, everyone belongs, that we are connected one to another, and that we must work together to weave together the fabric of community. We must remember the guidance from *The Little Prince*, Antoine d’St Exupery’s book for children of all ages, “that it is only with the heart that we can truly listen”. As we continually work to expand our circle of empathy we need 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, further disenfranchised across the digital divide? Can we grow to be, in the words of Parker Palmer, “gardeners of democracy”.

With the imperative for vigilance, in the fierce love, kindness, and determination of our community we know as Amanda Gorman has told us:

“For there is always light,
if only we’re brave enough to see it
If only we’re brave enough to be it”.

For those we work for, those for whom we will work for in the future, for ourselves and for each other, let us take to heart these words of Marge Piercy that have been a guiding force for our family:

“Be quiet and listen to the still, small voice within that speaks in love. Open to it, hear it, heed it and work for life. Let us remember and strive to be good. Let us remember to find what is holy within and without.”

I have such admiration in the leadership of everyone at The Boggs Center and confidence and enthusiasm that The Boggs Center will continue to grow and thrive in partnership with all of you.

To my colleagues and The Boggs Center and to all of you for the life of meaning you have given me, my gratitude is unbounded.

My heart is always with you, and I will hold this evening, all of you, and our years together in my heart.

Thank you, thank you, thank you.