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THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES
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

40th Anniversary Colloquium

Making the Ideal Real:
Love and Policy

Remarks by Deborah M. Spitalnik, PhD
Executive Director
Professor of Pediatrics
& Family Medicine and Community Health

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John F. Kennedy, when he was elected President in 1960 and at the urging of his sister Eunice Kennedy Shriver, began the first federal involvement and investment in service of people with what we now call intellectual disabilities. Central to that vision was the idea of university centers as a bridge between the university and the larger community.[1] Bringing the concerns of people with disabilities and their families into the university's mission of education and training, research, and service. And in crossing that bridge, the resources of the university would flow outward, strengthening the community.

The Boggs Center, as we came into being in the early 1980s, was part of the "second generation" of this vision, begun at the time when Home and Community Based Services were emerging as a service and potential federal funding direction. New Jersey, seeking to transform its long standing, heavily institutional service system, was seeking a source of innovation and support. The Department of Human Service's then DMR, now DDD — Division of Developmental Disabilities, Elizabeth Boggs, the New Jersey Council on Developmental Disabilities, and what is now Rutgers Robert Wood Johnson Medical School (then UMDNJ), collaborated, reaching out and working with the US Department of Human Services to create a center in New Jersey.

At that time, 900 children under 21 years of age were living in New Jersey's "State Schools and Hospitals," the large institutions we now call Developmental

Centers.[2] The only option for learning and activity for children with significant disabilities who did live with their families, was in segregated Day Training programs, outside of and not even administered by state or local education systems.[2] Early Intervention Services were just beginning in New Jersey and there were very few group homes or community residences. To be eligible for services from DMR, one needed to have a diagnosis and label of intellectual disability.

Forty years ago, could we have imagined that the longevity of people with developmental disabilities would be approaching the life span of the typical population? That people with IDD would be taught to read, to have access to the general education curriculum, and may be thinking about college? That individuals and families with lived experience would be the most powerful educators of our students?

Disability has not changed from those circumstances 40 years ago. If anything, we are seeing more disability, including the reported increased prevalence of autism spectrum disorder, as well as more severe manifestations of disabilities emerging.

Disability has not changed. It is we who have changed. We are continuing to learn how to listen harder and more, to support and intervene better, and to galvanize our efforts to always focus on the person. In the spirit of Maya Angelou, “I did then what I knew how to do. Now that I know better, I do better.”[3]

There are more opportunities and services than ever before in history. Opportunities have increased but so has complexity. Complexity in eligibility and admission processes, accessing services, and in the dire shortages of people available to provide support.

As we work to enhance early childhood development and make developmental screening universal, we are constrained by the lack of trained personnel in New Jersey and nationally. We have months and sometimes year-long waiting lists for diagnostic evaluations that could address parental concerns and get children on a path to the support that is crucial to their development and well-being. We also know that if your family’s primary language is not English or you are a child of color, these delays and disparities in access are even worse and heightened.

We encourage and support families’ understanding of the strengths and capacities of their loved one, but we when we assess eligibility for access, services, and budget, we highlight and make decisions based on deficits. As we collaborate with people with disabilities and families to chart a life course of inclusion and contribution and choice, we don't yet have adequate opportunities for an independent adult life, and even fewer for accessible housing. We struggle to create the circumstances and structures that would allow families to trust that their loved will have a life of well-being and meaning when they are no longer able or available to provide care.

As we struggle in our present systems, we know that despite the dedication and hard work of so many, we fall short in fiscal and human resources, and in meeting the demand for services. It gives us pause to try to understand who is not being touched by our systems and services, whether through Children's System of Care (CSOC) or the Division of Developmental Disabilities (DDD). By demographic population estimates, only a quarter to a third of adults with developmental disabilities are registered with DDD — that doesn't mean they are in need, but we don't know.[4] We know that there is an increase in caregivers ages 55 to 64 and above. How many aging and aged parents are caring for aging and aged people with disabilities, especially those who may never have had the benefit of education and services through the life span? Who else is not receiving support? Who is outside our embrace because they do not communicate in a traditional spoken voice? Or because of language spoken, or immigration status, or being part of an underrepresented community, being further disenfranchised across the digital divide when applications increasingly rely on technology?

As we look ahead, we celebrate a moment of pride that we live in New Jersey and our state has initiated and funded “Cover All Kids,” so that all children independent of immigration status, can have access to health care coverage. Going forward, let’s aspire to broaden that embrace to all adults with developmental disabilities.

Our purpose in gathering today in marking a milestone must be to take the experience of the past and use that learning to make a more valued present and future. One of the joys of teaching students is that it provides a prism, often reflecting what works and what doesn’t work for the people who are our focus. I am deeply indebted and motivated by our Leadership Education in Neurodevelopmental Disabilities — NJLEND fellows, some of whom are here today, whose loving commitments inspire us to wrestle with how far we still may be from the mark.

Do our deeply held values translate to opportunities for individuals and families? Can we tame, utilize, and improve our complex systems to create opportunities? Opportunities for contribution, friendship and connection, health, and wellbeing? Where families are supported and that there is trust in the stability and kindness of that support? Opportunities for adult life with independence that also honors our interdependence?

Fernald State School in Massachusetts is now closed. When I volunteered there as a college student, 3,300 people lived there. Bellevue Psychiatric Hospital in New York City, where I worked, was a chaotic and dehumanizing stepping stone for patients on the way to endless languishing at New York's large state hospitals. When I taught in the Boston Public Schools, before there was busing or a special education law, there were sometimes more children in my class than chairs. I came to study policy to grapple with the feelings of sameness and sadness these three systems evoked in me, despite their different expressed purposes and populations.

I believe the sameness and sadness came and comes from how we as a society hold each other; what we feel we owe or don't owe each other; and how we distribute or deny justice.

The structure of society emerges more sharply and prominently for those who are dealing with disability or other social disadvantages. Public policy and its impact upon our lives becomes more immediate and visible, more necessary, and essential. Having a disability, oneself or in our family makes us more dependent upon public policy, taking us out of the realm of the ordinary and the personal. The most personal, intimate aspects of life are at risk of becoming impersonal, controlled by others, with decisions made at a distance from us. Choices and opportunities quickly become limited or non-existent. The essential challenge for public policy, for disability policy, is to allow people to remain in the ordinary and the personal, and still get the supports and help they need and desire.

We become part of this community for myriad reasons. Some of us are born into this, through our own disabilities; some because our children or our sisters or brothers bring us here. Some out of a sense of social justice, others more randomly through employment or serendipity. Whatever brought us to this place, we are united in our search for the common good.

The federal Developmental Disabilities Act, the DD Act, creates the DD Council, Protection & Advocacy — Disability Rights, and creates The Boggs Center as a University Center for Excellence.[5] The DD Act is the poetry of our field. The DD Act reminds us that public policy can be a loving pursuit, engaged to create possibilities and opportunity. Crafted by the beloved, late Bobby Silverstein for Senator Tom Harkin's eloquent preamble, the Act reassures us that:

> "Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of society" (42USC15001)

The lines or borders that separate us are illusory or at least transitory. All of us are only a stop sign away, a random genetic mutation, or illness away. We move from one side of the desk to the other; from people who try to address needs, to those with needs to be addressed. That we are all in this together must guide our actions and become the basis upon which we as a society make decisions.

The federal DD Act and New Jersey's early adoption of developmental disabilities, appreciates the impact of early onset, lifelong disability, individual variation in cause and functional limitations, and the importance of coordinated services, permitting individual person-centered address of our needs. It binds us together in our commonality, helping us be visible in a society that often treats people with disabilities, particularly those whose disabilities begin early in life, as invisible.

Disability issues are not special interests, they are human issues, calling on us to exercise our collective will and humanity.

Ginny Bryant, earlier today in a beautiful video of her daughter Rachel Bryant and herself, described the poignant choices she and her husband Steve were confronted with when Rachel was about to begin school.[6] "Why would we go anywhere else?" was how she expressed their decision to enroll Rachel in their neighborhood school. Belonging, respect, sharing spaces, contribution, and choice are what John O'Brien, has described as the "Five Valued Experiences for the Good Things in Life."[7] The essence of inclusion is participating in the life of the community with access to the same experiences as one's age peers. Even the World Health Organization, in its International Classification of Functioning, defines disability in terms of participation.[8]

Our disability rights movement was borne of the crucible of the civil rights movement. The heart line from the Supreme Court's decision "that separate education is unequal education" in Brown v Board of Education, takes us straight through to the PARC Consent Decree, the Education of All Handicapped Children Act, and IDEA — the Individuals with Disabilities Education Act. From the Civil Rights Act to the Americans with Disabilities Act to the Supreme Court decision in Olmstead, and Ruth Bader Ginsburg's majority opinion that "unnecessary isolation is a form of discrimination."[9]

We have benefitted from the deinstitutionalization movement in New Jersey and nationally that helped people move to the community or remain in the community. Yet, we also know that being in the community is not the same as being of the community, with the richness of relationships and connection, ease, and familiarity, that make for the life we desire for our children and ourselves.

The nature of New Jersey as a state poses challenges for all of us: suburban and "suburban sprawl," limited public transportation, great disparities in wealth and access across zip codes, a lack of affordable housing and 600+ school districts. As government has been organized in New Jersey, beginning with the Department of Institutions and Agencies, the precursor to the New Jersey Department of Human Services, our history is of highly centralized disability services. Some other states placed people in large institutions by catchments or geography. Our original institutional placements and identity were more driven by gender or age: women to Vineland, men to New Lisbon; and babies and children to North Jersey, originally "Totowa." Our original structures didn't contribute to a sense of "coming home." We have had to search harder to create that sense of community to build a life of connection.

We need to create a paradigm of support where the expertise, intensity, and type of service available is independent of location and goes to where the person and the family are and want to be. The DDD Supports Program, the movement toward in-home mobile services in the Department of Children and Families, the Department of Education's emphasis on Community-Based Instruction, and the work of the Centers for Independent Living, are promising countervailing hedges against only providing support in separate places.

How can we be of our community unless we learn our community? When parents are facing the earliest decisions about their child's well-being, when people are emerging into adulthood, or aging with their disability, can we merge the Life Course perspective with access to expertise, creating a life of belonging? Can providers, helpers, employment specialists, support coordinators, companions, and instructors, also be of the community so that we can evoke these connections and support people with disabilities in being of the community?

We are part of a disability rights movement, a movement for justice and inclusion, honoring diversity, and pursuing equity. It is the advocacy of lived experience, first by families, and now joined by people living with disability, that has produced much of the change and opportunities that make a difference in our lives. Inclusion continues to evolve from the interplay of advocacy, the knowledge base and evidence, and our understanding and skills in how to provide support and intervention.[10]

The disability rights movement expresses our highest ideals, and aspirations. The sense of hope and possibilities brings us together in common purpose and shared experience.

How do we go from the poetry of the disability rights movement to the prose of policy implementation to make services and supports accessible and available?

The DD Act was born out of collaboration: Elizabeth Boggs of New Jersey, mother of David who had IDD, and Elsie Heisel of Ohio, mother of Robin who had cerebral palsy, collaborated across their respective roles as Government Affairs Chair for the ARC and Government Affairs Chair for United Cerebral Palsy. They made common cause with each other, believing that taking a functional approach to disability and decreasing competition for resources across groups would help all boats rise.

Elizabeth Boggs expected that the monies for long term disability services that would come to the states from the federal government would flow through the DD Act, making real its vision and world view. Unlike in the *Princess Bride*,[11] where the reader can select a different ending, federal funding for services in the states did not come through the DD Act but became part of Medicaid, with its origins in facility-based services, and what is described as the "institutional bias." Despite the power of waivers, for which we all owe a great debt to Julie Beckett, mother of Katie Beckett, it is still both amazing and a disappointment to national advocates that community is not the embedded direction and that institutions would require a waiver.

We look toward the full flowering of the Home and Community Based Settings Rule to bring us closer to the vibrant lives that are possible when we support people to truly being of the community.

Medicaid is a federal-state partnership, and what Medicaid looks like for people with disabilities and all beneficiaries depends on where you live. We appreciate the leadership of Commissioner Adelman, Assistant Commissioner Jennifer Jacobs, Greg Woods in partnership with Assistant Commissioner Jon Seifried and DDD in making decisions based on a series of North Star principles, striving to get to what Jennifer calls the "true true."

This is the policy context for our community, so we need to educate ourselves and each other to understand Medicaid and utilize the opportunities we have for stakeholder input and support of due process. On a personal note, I would add that Medicaid brings together two strong interests of mine: policy and shopping. As a disability community we do well to be guided by the mission statement of that great New Jersey entity Syms and its leader Sy: "an educated consumer is our best customer."

In making the ideal real, we are often confronted with the unintended consequences of good intentions.

Working in Early Intervention during my clinical training, I had the privilege of facilitating a group for mothers while their children received therapy services in another part of the clinic. I learned a lot about parental love and was able to bear witness to the meaning, power, and uniqueness of parent to parent support: what our colleagues at SPAN practice and continue to teach us. When Early Intervention Services nationally became Part C of IDEA, in the spirit of Least Restrictive Environment which we affirm, Early Intervention began to be delivered in “natural environments”: homes, day care centers, and preschools. More typical of one’s age peers but breaking that chain of parent connection that has historically been such a source of sustenance for so many families, with natural environments sometimes contributing to isolation and loneliness. The benefits for children of intervention in the natural environment may at the same time mitigate an important source of social inclusion for families.

Over 30 years ago, The Boggs Center, in collaboration with the Family Support Coalition, DDD, and the participation of leaders in family support from across the country, worked diligently and respectfully to hammer out the “Principles for Family Supports in New Jersey.” These principles captured the aspirations of families to be able to raise their family member at home and within their family, reflecting the national tenor “whatever it takes” — a mission statement and a rallying cry. The progression from movement to legislation to program services with regulation, budget, and eligibility criteria, epitomizes the difficulty in staying in the personal when we are forced to move into a public and policy context to address even our most basic needs.

From the early days of self-determination in services in New Hampshire and promoted by the Robert Wood Johnson Foundation, to self-direction as now both a service and funding option, we experience the tension between the aspirations of the people for whom we work and the responsibilities of government for stewardship and accountability and equity. The ideal and real continue to challenge us.

That which we hold dear in disability supports, even when they are not yet equal to the need or delivered as we wish to see, represent changes in paradigms. In one of my favorite New Yorker cartoons, the devil is standing in front of 2 doors — one marked “damned if you do”; the other, “damned if you don’t.” Door 1, “damned if you do,” could represent a complete paradigm shift, the way the world changes so dramatically that we can’t see the world as it was previously, making it harder to know or remember that the world has not always been this way. We are no longer aware that what we think, experience, or utilize as basic, standard, accessible, or available, was not always this way. That education for children with disabilities was not a right or entitlement, that people with disabilities were not able to work, or that any of us approximately 100 million Americans with pre-existing conditions might not have had access to health care coverage.[12]

I am deeply concerned for the fragility of that which we hold most dear. We have counted on the right to education for children with disabilities, as long as we had had have the right to reproductive choice.

At Door #2 — “damned if you don’t” — less of a complete paradigm shift, we are also at risk when we don’t make more fulsome commitments to change. As new models and approaches to disability supports emerge, we often struggle to fully incentivize these changes and embrace these innovations, to make them more completely available to more people. As Jon Seifried, Assistant Commissioner for DDD is often tasked to do, we are “building the plane while flying it.”

We reside or provide in a netherworld of mixed approaches. We are an Employment First State, but most of our resources for what people with disabilities do with their time goes to day programs. We promote inclusion but congregate or concentrate specialized expertise rather than broaden access. By the ways we fail or are unable to fully commit, we are not able to learn by doing, to refine our approaches, and to make improvements. We risk cynicism, discrediting of approaches, and dismissal of possibilities because we haven’t fully explored and developed what we do.

In 2017, with my colleague Carrie Coffield, we led a group of 12 interdisciplinary fellows to Washington, DC to learn more about policy and meet with our Congressional delegation. There were major demonstrations by disability and other advocacy groups to protest efforts to repeal the Affordable Care Act (ACA) and diminish Medicaid. Since the ACA — Obama Care — was signed into law in 2010, there were 67 attempts in Congress to weaken or repeal the Act. None of them were successful per se, but the threat to all of us is enormous. For people with disabilities and other vulnerable groups, this is particularly critical because Medicaid is embedded and inextricably tied to the Affordable Care Act. That Spring was a heady exciting time to be in the middle of a peaceful, spirited expression of democracy, with leadership from activists with lived experience. Though none of these legislative repeals came to be, other destructive changes have come about administratively and budgetarily. The excitement at the time and the lack of legislative outcomes has given rise to the myth that it was advocacy that beat back those changes.

In my view these changes weren't prevented because of the power of advocacy and the visible displays of unity, concern, and commitment to people with disabilities and other needs.

I contend that at that time the proposed changes: loss of benefits, loss of access, co-pays, and work requirements, did not come about through

Congressional action because of activism, but rather that some, many of whom are still in Congress, did not consider the changes harsh enough, draconian enough.

I think we, as a disability community, may be in for a rough ride by those that do not share our view of the common good and do not agree that we have a responsibility to each other and for each other, to invest in and care for each other.

At this divisive time in history and the enormity of the challenges we experience in so many aspects of life, it could feel elusive, almost impossible to effect change; to even in some small way chip away at inequity and create opportunity, to make the real work for people as we strive or aspire to the ideal. We have an ethical responsibility to move forward with optimism, to share that optimism and build resilience, especially when the resolve of those among us is continually and painfully tested. The strength and bravery in this room and the disability community is captured by 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."[13]

Ginny Bryant described how the desire to support an inclusive life emerging into adulthood and navigating across complex systems is creating new challenges and needs that we have not fully realized. As we eagerly await the pictures and hearing about Rachel's prom, could the richness of our being gathered together here today point us to a path supporting young adults in charting their course, forging a truly collaborative approach to transition, and all of being a resource to families as they move into this new territory and life stage?

We could support young adults and families, in the words of William Penn, with "Love and Information."[14] We could "walk alongside" and we could work to transcend the boundaries, practices, and discontinuities of all of our systems that converge at transition. We could join with young adults and their families, sorting out, braiding, and blending our responsibilities, not expecting families to figure things out on their own. We have an opportunity to make a leap forward and make the last years of educational entitlement both vibrant and productive, approaching adult life grounded in skills and supports and with high spirits.

We can apply what Brené Brown has taught us about empathy, bringing more nurturance and empathy to the life stage of adulthood of the individual and for the family, as we have worked to do for younger families.[15]

When in class we gift our students with a “magic policy wand” to inspire us to improve policy and life opportunities, all their recommendations honor the person, the family, and the community: the common good.

We know there are no ideal policy wands or solutions or easy answers. What we do have is each other and our ability to listen in respect and kindness, to and work together.

For those we work for, those whom we will work for in the future, for ourselves and for each other, let us take to heart these words of Marge Piercy:

> “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.”[16]

Together we can create a world where everyone belongs.

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Medical School

The Boggs Center on Developmental Disabilities
Department of Pediatrics
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