

*Love and Listening:  
Weaving the Fabric of Community*

*Remarks by Deborah M. Spitalnik, PhD*

*Executive Director and Professor of Pediatrics*

*30<sup>th</sup> Anniversary  
Colloquium*

*The Power of Listening in Building a Valued Future*

*September 27, 2013*

The Boggs Center came into being to serve as a source of innovation, to train new generations of personnel, and for those working in the field to have opportunities to develop new skills and renew themselves, reconnecting to the reasons they were drawn to work with people with disabilities. Matt Byra was seven years old and in a day training program, completely separate from the educational system. 945 children under the age of 21 lived in “State Schools and Hospitals,” what we now call Developmental Centers. Children were 15% of the 5,942 people living in large congregate institutions. Only people with intellectual disabilities, then referred to as mental retardation, were eligible for services from the Department of Human Services.

Matt Byra is now growing toward middle age, living in a home he shares with a family who has become his caregivers and friends. Two developmental centers are closing and no children live in any of New Jersey’s institutions.

Thirty years ago, could we have imagined that employment would be considered the desired outcome for adults with disabilities? That individuals with intellectual disabilities would be exploring college, as a form of post-secondary education? That Autism Spectrum Disorder would be the fastest growing disability diagnosis?

Given the upward trajectory in building community residential services and an elaborated vision of adult life we were seeing 30 years ago in New Jersey and

around the country, we would not have predicted that most adults with disabilities would live with their families for most, if not all, of the life span of the family.

We would not have anticipated that the life span for individuals with developmental disabilities would now be approaching the life span of the typical population, and that transition to adult health care would be one of our most pressing challenges. We would not have predicted this tidal wave of young adults, the “IDEA Generation” who having had the benefits of education, that they along with their families, would have higher expectations for their adult lives.

As we make progress, new challenges arise.

We experience that in technological advances. My early clinical work and research before I came to The Boggs Center was in PKU (phenylketonuria), an inherited metabolic disorder. Our challenge was to prevent intellectual disability. The success in the field created the next challenge: young women with controlled PKU growing up without impairment, wanting to have families but at risk of maternal PKU, which can damage the developing fetus.

Progress and then new challenges arise. From the survival of “micropremies,” smaller weight babies born at earlier gestational ages, to the survival of people with severe traumatic brain injuries, new needs for support over the life span have come to the fore.

What I’d like to focus on today is this tension between progress and emerging challenges in the ways we provide services and supports.

Our most progressive ideals, and how they are incorporated in services and day-to-day life, may feel like polarities for many individuals with disabilities and families. The gap between our collective vision and their reality may seem like a contradiction, or at the very least, a stress or tension within the system and in peoples’ lives.

We are committed to person-centered services, but for our funding we must rely on Medicaid, with its intricate requirements and regulations.

Families continually tell us they want and need someone to walk alongside them, to help negotiate the complexities we have created in our efforts to provide services. Yet across systems and titles: “coordinator,” “care manager,” or “navigator,” we’ve never been able to enduringly provide this support in the quantity and manner it has been requested, despite our best intentions

New Jersey has one of the oldest and earliest traditions of providing of special education services, and yet we remain one of the most segregated states educationally.

We have inspiring public policy with the Governor's commitment to Employment First, yet in New Jersey and across the country the number of people in employment has been decreasing.

Our newly developing Supports Program reflects our commitments to family and community, but there are still huge inequities in the level of resources devoted to congregate care.

In our sincerely held values and ideology, we may not be addressing people with more significant needs for support. Severity of disability may become a source of segregation, with the desirable innovations we promote not available or accessible to those with significant disabilities and support needs and their families.

Despite our shared commitment to diversity and inclusion and the pursuit of cultural competence, many of the values permeating disability policy may not be as equally held across different communities in our society. I am continually indebted to Sarah Mitchell, former director of Disability Rights New Jersey, for her insights as part of New Jersey's team at a national academy on

inclusion 15 years ago. Individual choice and self-determination may be the dominant values of person-centered policy, but may contradict dominant values in African-American culture where the family is the focus, not the individual.

To wrestle with these paradoxes, we came to today's theme of listening. In his book for children of all ages, The Little Prince, Antoine d'St Exupery reminds us, "that it is only with the heart that we can truly listen."

We can draw inspiration for this wrestling from the federal Developmental Disabilities Act, the public policy poetry of our field. Senator Tom Harkin's embracing preamble reminds 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)

I draw both inspiration and solace from Quaker principles, another set of tools in wrestling with these polarities and tensions. William Penn, in the mid 1600s wrote in Fruits of Solitude, "We are too ready to retaliate, rather than forgive or gain in Love and Information."

The last thirty years represent more opportunities and resources for people with developmental disabilities than in all of previous history. Despite that, we know how individuals and families still desperately struggle to achieve their rights and the supports that they need. We have a moral imperative to act out of, what I hope, is an ascending spiral of knowledge and experience, continually honing our skills and commitment to listen to people with disabilities and their families.

The federal mandates that George Jesien and Andy Bacon so ably discussed this morning, animate us at The Boggs Center as a University Center for Excellence. We have recast these as “habits of the heart,” a term borrowed from D’Toqueville (1835) in his observations on American democracy.

Our “habits of the heart” are the questions we continually ask ourselves as individuals, and collectively as an organization:

- How do we ensure that the work of The Boggs Center is guided by the aspirations, needs, and perspectives of people with disabilities and their families?
- How do we educate the next generation of people in our field?
- How are we getting information to the people who need it, in a way that is useful to them?

- What will be the contribution to the knowledge base of the field?
- How do we learn if what we do is effective and meaningful?

Only in practicing “habits of the heart” can we move forward with conviction. Returning to William Penn’s terms, to act out of love and information, we need listening as the foundation.

Understanding behavior, with its original research base in experimental animal studies, is the scientific basis for the possibilities for full inclusion in community life, and underlies progressive public policy. For more than four decades, the behavioral paradigm has been the foundation of intervention. This early body of knowledge was applied in Diane Bricker’s work in language development with young children, and Marci Hanson’s work in social and skill development in children with Down syndrome. The evolving sophistication of the behavioral paradigm gave rise to Tom Bellamy’s work at the Specialized Training Program at our counterpart UCEDD at the University of Oregon. His work, and that of Mark Gold’s, formed the basis for our understanding that people with intellectual disability, including significant disabilities, could be productively employed.

Applied behavior analysis and the highly developed technology of systematic instruction provide the evidence base for Positive Behavior Supports. The



Boggs Center takes great pride in having introduced Positive Behavior Supports to New Jersey, from the first season of the Developmental Disabilities Lecture Series in 1984, David Pitonyiak's work at North Jersey Developmental Center, and extensive consultation from our late dear colleague Herb Lovett. A third of our Center's efforts and people are now dedicated to Positive Behavior Supports— in schools and in community services.

As an intervention approach, Positive Behavior Supports sees behavior as a form of communication. Positive Behavior Support is a testament to listening: to finding out what is important to people and then enriching the environment to make it possible for people to have what they want and need. Positive Behavior Supports in Schools has developed highly structured processes and training to empower students, teachers and administrators, to work together in creating the circumstances for learning and constructive action, and making it possible for schools to include all learners, including those with disabilities. In the community, parents and providers have been helped to learn to use Positive Behavior Supports to enable families to function, and children to grow. As we move to further implement PBS approaches for individuals moving to the community from developmental centers under Olmstead, we strive to demonstrate how listening can be an act of love.

The Direct Support Professional Workforce represents some of the central challenges in our field and is another exemplar of the importance of listening.

Through words and when those are not available, behavior, people with disabilities tell us they want stable, caring, consistent support in their lives. Whether it's to help buy and cook the food to one's taste, understanding personal dreams and aspirations, or performing the most intimate and personal routines of daily life, people need reliable, skilled people in their lives. People want and need other people who will learn to listen to them— whether a spoken enunciated choice or a tilt of the head which signals tiredness or the need to change activity or position.

Through the work of Beth Barol in Pennsylvania and our former colleague Bill Gaventa, we know how much continual loss and grief there is for people with disabilities, as those who provide care go in and out of their lives. Who among us would choose to have the most personal and intimate aspects of our lives conducted by strangers? Families continually ask themselves and all of us, who will take care of their child when they're gone?

Through the work of the NJ Partnership for Direct Support Professional Workforce Development, and for the last 8 years in celebrations of Direct Support Professional Recognition week, we have heard the voices of Direct Support professionals express how important education and training are to them. Direct Support Professionals (DSPs) say clearly that they want to be better educated and increase their skills to better serve the people with

disabilities for whom they work. Many DSPs work two jobs in order to be able to eke out a living for themselves and their family. Workers in the fast food industry make as much, or more than DSPs. In the mid 90s as part of Welfare reform, there was the possibility of using TANF funds for job training. We thought it was a perfect vehicle for attracting caring people into direct support work, with a ready-made path, and a source of funding for training. We found that we could not access those funds, because training someone to become a direct support worker does not lift someone out of poverty. Where is the social justice in that?

Nationally and in New Jersey, we are in the process of redirecting Long-Term Services and Supports from Institutional to Community care. It's estimated that the country will need 1.6 million additional Direct Support Professionals by 2020, at the same time as we are facing a shrinking labor force and the tsunami of baby boomers who are aging and living longer, who will need and demand assistance and care. Amid this competition for resources and workers will the voices of people with developmental disabilities and their families for quality support and skilled, equitably compensated caregivers be heard? Can we listen to others who are similarly situated and make common cause across disabilities, aging and child care, supporting dignity for all?

How do we rearrange our priorities so that our financing honors what's important to people and aligns that with resources?

The organizing principle for today's colloquium is the imperative to listen to people with disabilities and families — the people for whom we work. I want to shift the focus to our responsibilities as professionals, in how we ask people to listen to us.

When we share our beliefs about a world of support that is personal, directed by the individual and family, where disability is not a handicap but rather the need for additional support, are we raising expectations and sharing vision or are we denying the reality of most people's experience? Are we creating hope for the future or inducing despair at the state of the present?

What are the balances inherent in appreciating realities and our advocacy responsibility to contribute to shaping new and better realities?

When we ask people to listen to us, we must keep in mind that listening, for all of us, occurs through our cultural lens. Employment for people with disabilities, for example, may not have the same meaning in different cultures. In the majority of professional culture, we see employment as promoting growth and opportunity. To many people of different cultural backgrounds, promoting employment may be seen as uncaring— turning our back on, or denying, or not acknowledging the family's responsibility to care for and protect the family member with a disability.

Maya Angelou has written, “I did then what I knew how to do. Now that I know better, I do better.”

In Willowbrook, New York State’s large institution was subject of one of the first deinstitutionalization cases in the 1970s. In the 1950s, many of the children who had been placed there were injected and infected with the Hepatitis virus for the purpose of conducting research. It is why we now have Institutional Review Boards for the Protection of Human Subjects, but also the continual individual, professional responsibility to act ethically and humanely, and in accordance with scientifically accepted standards of practice.

In areas of diagnosis, including the attribution of etiology and treatment recommendations, our history has caused great pain. Although it was not any one in this room, it was the collective professional “us” who communicated the erroneous belief inherent in the term “refrigerator mother.” Can we even imagine, let alone ever erase or even repair, the pain of mothers who were told that their children’s Autism was because of their lack of parental warmth and maternal attachment, not, as we now know now, their child’s atypical neurological makeup or “wiring?” These may be historical examples, but similar considerations persist.

What about the child with disabilities who is denied or discouraged from an organ transplant? The child whose parents are urged toward DNR orders

because the life of a person with a disability is not considered a life worth living?

Of the learnings our students, some of whom you will hear from later, take from families, the learnings about diagnosis are particularly compelling. Our students see the long-term impact on families from how the family learned about their child's diagnosis. Students know that one day they will be responsible for communicating a diagnosis. We know that there is much communication that is less than adequate. Even when delivered compassionately, the diagnosis often stands alone — without addressing the desperate needs for information and support of the family, when they are plunged into this new world of disability. We must prepare our students to act with information, and support them in acting with love.

The issue that is the most challenging to our ability to listen and act in love and information is the continued existence of large institutions. New Jersey has enunciated its commitment to close two institutions and expand community services. There is fierce opposition by family members connected to developmental centers and also, in some cases, staff, including a lawsuit counter to the Olmstead consent. Although thirteen states no longer have any large public institutions, nationally there is a highly organized, highly vocal backlash against institutional closures which threatens to derail or mitigate reauthorization or passage of legislation that strengthens community services.

Kathy Roberson's poem, "Family Snapshots," grounds us in the contrasts of history and present reality. Kathy juxtaposes the possibilities for her daughter Katie with the life of Katie's great, great uncle, Emerson Trowbridge Cottner, "Buddy" to his family. Buddy had been placed in Pennhurst in 1931, shortly before his 18<sup>th</sup> birthday. He died there, six years later at age 24, a not uncommon occurrence prior to the advent of antibiotics. In 2004 when Katie's great grandmother requested Buddy's records, she received a kind and compassionate letter from Greg Pierman, a former employee of Pennhurst, a Pennsylvania institution, the subject of two major deinstitutionalization cases, and which is now closed. He wrote,

"I think it is important for you to understand that the decision to place your brother in Pennhurst was one that society endorsed at the time and was made necessary by the lack of other alternatives. Today, we know that people like your brother can live full and productive lives in their home communities."

We try to take solace from Maya Angelou, "I did then what I knew how to do. Now that I know better, I do better."

David Boggs was institutionalized in 1952 — he was 7 years old. His parents came to this decision, because David rarely slept, spending his nights roaming the house, exploring and ingesting the contents of medicine cabinets and the refrigerator. David's father, Fitzhugh Boggs, began falling asleep at work and then having car accidents, from his lack of sleep. At best, Elizabeth and Fitzhugh traded off sleeping shifts and supervision shifts. In the 1950s, sleep

disturbances were the primary cause of institutionalization, especially of children. We now have family support that could help with in-home respite, so a family could sleep, at least some nights. We know how to do better and we do do better, but I wonder how many of the parents in this room still don't sleep through a night?

There is a clear legal and ethical imperative for community living for all. It is the right of individuals to not be segregated: to not be discriminated against on the basis of disability. It is an issue of empirical evidence that people can both develop and exercise a higher degree of adaptive functioning when they live in more personal and typical places. It is also an issue of economics, not in the distorted way that it is often caricatured in argument — that states are trying to take things away from people. Rather, that investments in propping up arcane physical infrastructure means that we have fewer resources to devote to the press of human need of all our citizens with disabilities and their families. We are all grateful for New Jersey's policy decision to reinvest savings from institutional closures into community.

When I was David Boggs' guardian from 1996 upon Elizabeth's death, until David's death in 2000, it tore at my heart whenever I left him at the large institution in which he resided.



How do we understand and connect to the hearts of those families who made the painful decisions to place their family member in an institution? It must never be far from our hearts and thoughts: they listened to us and our advice at that time.

Physicians told families when their child was born, “*don’t take him home*” — “*it will ruin your family*”. “*Don’t see her — don’t hold her, just place her and go home and get pregnant again.*” There are families still living in New Jersey where brothers and sisters didn’t know they had a sibling. At Totowa State School & Hospital, now North Jersey Developmental Center and scheduled to close, there was a nursery, an actual nursery, with cribs for newborns and babies and highchairs for toddlers. They listened to us.

Can we find the courage to open our hearts, to connect to the hearts and pain of that history, while affirming our commitment to community living for all? In approaching those with whom we disagree, or who disagree with us, can we find guidance and inspiration from Abraham Lincoln’s words in Speaking of Southerners, in Springfield, Illinois in October, 1854: “They are just what we would be in their situation?” “They are just what we would be in their situation.”

Can we listen and engage with each other in ways that open our hearts and permits us to “expand the circle of our empathy?”

As we strive to be compassionate, reflective and vigilant, to avoid engaging in the absolutes as in the past, can we proceed in both action and policy grounded in love and information?

As we struggle to keep our hearts open and to find common ground, it helps to remember that we are all in this together — our destiny is shared and none of us are immune. In the flash of a diagnostic image or a stop light ignored, we become someone with an illness or a disability — we become someone with a pre-existing condition. We go from sitting behind the desk, to sitting in front of the desk. From being the person offering help, to the person needing help.

At last year's Direct Support Professional Recognition Week, Patroba Onyango, a dedicated Direct Support Professional at the Arc of Middlesex County, spoke passionately of how important it was to him as a DSP, to participate in the DSP Career Path and take courses in the online College of Direct Support. He did this because of his dedication to the people he served in his job. When his wife went into premature labor and gave birth to their daughter with Down syndrome, he knew that now he needed to use what he had learned in the most personal way.

Thirty years from now, when our successors are gathered in a similar, perhaps by then, virtual celebration, will they be able to see that we did learn to listen to each other?

Let us demonstrate our understanding that what is important to all of us is both shared, and at the same time, highly specific and highly personal.

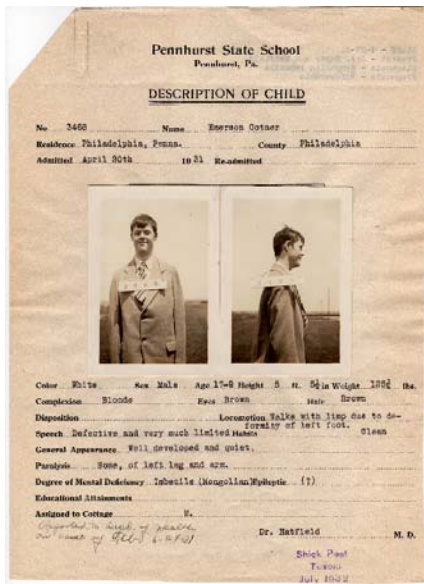
Let us together craft public policy that, in its content and results, creates services, supports and enables lives that are, in the wonderful words of the late Commissioner of Human Services, Ann Klein, “good enough for me.”

Can we heed William Penn’s exhortation, “let us then try what love will do?”

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.”

Thank you for your attention this morning, but even more so for the privilege of working with all of you these past thirty years.



## Family Snapshots

Picture this: 1931  
a young man shyly  
smiling, standing  
straight in a slightly oversized  
suit, tie neatly  
knotted, a placard around  
his neck, number 3468,  
almond-shaped eyes the only  
clue, and below, the labels  
*Imbecile (Mongolian)*

And this: 2004,  
an elderly woman opening  
file number 3468, requested  
for years in politely penned  
letters, two faded pictures  
bringing it back... *Pennhurst  
State School*, her brother  
smiling...not knowing then  
how decades later, even after  
husband, children, grandchildren,  
great-children, this small, hidden  
missing of him would persist.

I hold them close now, those  
photographs of Buddy, this one  
of my daughter, who in another time  
might have been there; here  
she's sitting on the back porch  
in a bright red sweater, our bodies  
leaning into each other, fingers tightly  
entwined, not bothering to look  
towards the camera, laughing  
without restraint, content for an  
instant that was more than enough,  
so much more than enough.

© Kathy Roberson



# THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

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

## *30<sup>th</sup> Anniversary Colloquium*

*The 30<sup>th</sup> Anniversary Colloquium is funded through a private bequest*

# RUTGERS

Robert Wood Johnson  
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

<http://rwjms.rutgers.edu/boggscenter>  
p. 732-235-9300  
f. 732-235-9330