

# Love and Public Policy

Remarks by

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MEDICAL SCHOOL

University of Medicine & Dentistry of New Jersey

*A University Center for Excellence  
in Developmental Disabilities Education, Research, and Service*

20<sup>th</sup>  
*Anniversary  
Colloquium & Celebration*

*Disability Policy: Honoring the Past, Shaping the Future*

May 19, 2004

I want to chronicle some of the highlights of public policy in the past 20 years directly affecting people with developmental disabilities and their families, systems and providers. Most of what I'll discuss is at the state level, meandering into federal policy as it affects what we do in the Developmental Disabilities system in New Jersey. The title, *Love and Public Policy*, comes from 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.

Of all the debts we owe the late Justin Dart, my favorite is how he modeled for all of us, the loving nature of true advocacy.

We come to this endeavor for myriad reasons. Some of us, through our own disabilities, were born into this; some because our children or our sisters or brothers bring us here. Some of us come out of a sense of social commitment-others more randomly through employment or serendipity.

Whatever the pathway that has brought us here, there is a place at the table for all of us. We must honor each other's experience.

While we must honor each other in the disability community, it is the larger society that we must influence to ensure the realization of rights and opportunities. Our shared work is to make tangible the mutuality of relationships and the caring of communities. We need to

embrace each other and cultivate and sustain strong allies beyond the disability community to make real the social contract.

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”. Three hundred and twenty-five years later, the federal Developmental Disabilities Act reminds us that public policy can be a loving pursuit, engaged to create possibilities and opportunity. As Senator Tom Harkin’s eloquent preamble to the Act reassures us:

“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 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. Disability issues are not special interests, they are human issues.

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.

The last twenty 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, combined with increasingly honed abilities to listen to people with disabilities and their families. We can only move forward with conviction if, in D'Toqueville's terms, we are practicing "habits of the heart" (1835). Returning to William Penn's terms, we must act out of love and information.

In the past 20 years some of the most important and dramatic changes across the field have been paradigmatic: once we have seen the world differently we cannot imagine the world any other way. Once the paradigm shifts it becomes part of our consciousness. Developmental disabilities as a unifying construct for a heterogeneous group of individuals whose disabilities originate early in life and persist throughout the life span is such a paradigm. When we affirm that severity of support needs does not have to determine where a person lives and how these needs are addressed, our worldview has changed and our strategies must also.

Grappling with issues of equity are an imperative we can no longer ignore. Self-direction and choice for people with disabilities and their families must be at the core of everything we do.

I now see much more gray hair staring me back in the mirror and in the audience in front of me than I or we did 20 years ago. For the first time we are now seeing gray hair in the people we serve. The life span of people with developmental disabilities is now, in effect, the same as for the general population. This is a significant accomplishment. As we look ahead we also face new challenges as caregivers age, individuals with disabilities develop the health changes and secondary conditions that accrue to aging, and individuals wish to age in place. And all of us face difficult end of life decisions.

When The Boggs Center started in 1983, then called the University Affiliated Program of New Jersey, it was only eight years after the passage of P.L.94-142, the federal Education of All Handicapped Children Act, the precursor to the Individuals with Disabilities Education Act (IDEA). It was nine years before the passage of the Americans with Disabilities Act and eight years after the Willowbrook Court decree.

In New Jersey, Early Intervention Services for babies and toddlers had just begun. Started with demonstration funds from the Developmental Disabilities Council, the programs were turn keyed to state funding from the Departments of Human Services, Health and Education. Now there is a mix of state and federal funding that supports these services.

Children with severe disabilities who were not in State Schools, the congregate institutions we now call Developmental Centers, lived with their families and attended Day Training Centers. The life path for children with severe disabilities led to segregated Adult Training Centers. So far from the fabric of our communities, children with severe disabilities did not even receive an educational classification, but bore the label “day training eligible”, reflecting not their needs or learning styles but rather a program model. We have a virulent tendency in New Jersey to turn needs and ideas into programs or models into which individuals must fit. Through self-directed services, we are beginning to work hard to curb this tendency.

Although segregated, it is clear that these Day Training programs enabled many children to remain at home with their families—families who wanted them to be at home. Many of these children would not have survived had they been institutionalized. Here, as nationally, it was the combination of having a program during the day and the availability of Supplemental Security Income (SSI) that enabled families to keep their children at home. These children are now adults, many of whom are as severely disabled as their counterparts living in institutions. These adults continue to live at home with their aging parents who have been caregivers for decades. Many are on waiting lists and very much in need of community supports. Many are also unknown to the service system.

In 1982, 945 children under the age of 21 lived in New Jersey’s State Schools and Hospitals, representing 15% of the total institutional population. As of 2003, twenty children still lived in New Jersey Developmental Centers.

Prior to and independent of the founding of The Boggs Center, a lawsuit was brought against the state by the Mental Health Law Project in D.C., (now the Bazelon Center). The suit was brought on behalf of eight named plaintiffs living at NeuroPsychiatric Institute. This lawsuit never achieved class action status, and resulted only in limited degrees of individual relief for each of the plaintiffs.

New Jersey has never had a major institutional litigation. That's either the good news or the bad news, depending on your perspective. Good news that New Jersey's services have never been driven by the often slow pace and sometimes arbitrary nature of the courts making change. Bad news that there has never been the energy and imperative for community services that would derive from a Court decision or court order.

Independent of this suit, this facility, which became North Princeton Developmental Center, has now been closed with everyone who lived there having moved to the community.

In 1983, the year the Center was founded, no Family Support programs or employment programs existed for people with developmental disabilities in New Jersey. Children with autism, then the responsibility of the Division of Youth and Family Services, were just beginning to be served by the Division of Mental Retardation under the terms of a written, inter-divisional agreement within the Department of Human Services.

Active deinstitutionalization of state schools and the corresponding development of group homes in the community was a function of New Jersey entering the Intermediate Care Facilities-Mental Retardation Title 19, ICF/MR program in 1978, later and more reluctantly than our neighboring states.

Developing group homes made it possible to move some people out of institutions, enabling the state to move individuals remaining in the state schools to the freed up space.

Renovations could be accomplished in the remaining spaces to enable New Jersey, by upgrading space and ending overcrowding and concentrating staff, to meet certification standards in the state schools and begin to receive federal reimbursement.

In 1977 the state school population was at 7,932. As a result of this deinstitutionalization push, by 1983 the population had decreased by about 2,000 people to 5,942. It has taken us 20 years to decrease the Developmental Center population and enable the same number people to live in the community as moved in that initial five year period.

The increase in life quality for the people who have left institutions both in New Jersey and nationally is significant. Ideas and practices that were held at the time have turned out to limit growth for many individuals, as well as limiting the responsiveness of delivery systems to the wishes of people with developmental disabilities. Professionals convinced parents that group homes were permanent life-long placements; similarly to the way, decades before, parents were convinced of the necessity of institutionalization. While parents needed to trust



in the stability of the newly developing community system this also created obstacles for individuals who might want to move to living situations with more independence. With group homes well funded with state program dollars to provide furnishings and other amenities, subsequent moves to more independent living, with more reliance on the use of individuals' SSI, has often seemed to represent a decrement in the quality of life rather than an increment in independence and opportunity. Today as our system wrestles with individual financial contributions and issues of equity in the distribution of resources, we can see the roots of these struggles in the earlier community system.

From the early to the late 80s, the delivery system struggled with the continuing threat of decertification of the state schools/ developmental centers by the Health Care Finance Administration (HCFA) now the Centers for Medicare and Medicaid Services (CMS). With the recent actual and threatened decertifications from CMS and the intervention of the U.S. Justice Department in New Lisbon Developmental Center, the state and the DD community must now struggle with the inherent contradiction between individual needs and large congregate settings. While the State cannot abrogate its responsibility in assuring safety and striving for quality services for people who live in Developmental Centers, it is of concern that the investments necessary to maintain certification may continue to perpetuate institutions in New Jersey.

Nationally, we have seen a shift where 55.4% of Medicaid spending on long term care for people with developmental disabilities is spent on Home and Community Based Services

and 48.4% on institutional services through ICFs/MR-institutions (Prouty, Smith & Laikin, 2002). In New Jersey, it is almost exactly the reverse: we spend 46.5% of these federal funds on Home and Community Based Services and 53.5% on ICFs.

Looking at Fiscal Year '03 caseload and budget, New Jersey's Developmental Centers served 3,300 people and received 35.3% of the budget. Community residential services, serving 6,500 people, received 57.1% of the budget. At the same time, 6.6% of the budget went to the 18,000 people living at home with their families.

The complexity of the developmental disabilities and the complexity of service systems raise the need for assistance in negotiating and securing services. Individuals with disabilities and their families continually express the need for such assistance and the lack of availability of meaningful help and connection. Despite this glaring and expressed need, the functions we call case management have never been effective. We need only look at the number of task forces and work groups that have been mounted in the last twenty years to address case management issues to know what families know on a daily basis: we have not yet created reliable, stable, knowledgeable connections and alliances to help people achieve the lives they want and need.

The Division of Mental Retardation's Case Management System was developed by declaration. One day in the early 1980s, it was announced administratively that the social workers of the Bureau of Field Services were becoming case managers. No role definition,

administrative structures or adequate training was developed to support this shift in outlook or function. The pressure for rapid deinstitutionalization also disempowered or at least did not empower case managers, giving them no meaningful role for planning services or living arrangements for people leaving institutions. Case managers “inherited” individuals as cases once they were “placed” in programs, without authority to plan or authorize resources. Unmanageable caseloads, lack of impact in influencing services or placements, and lack of control of resources have converged to make state case managers bear the debilitating combination of responsibility without authority.

As New Jersey has been moving toward self-directed services we have had different experiences with case management, supports brokerage and supports coordination. We need to learn from these experiences and offer better options for families to get what they need. We also need to enable people who work in the state system to make a difference in the lives of people with disabilities. We will be unable to retool the system toward self-direction for everyone if we don't figure out how to support individuals and their families to connect to the things they need and create accountability for individuals achieving the outcomes they desire.

As the community system has expanded, the need for infrastructure to support people living in the community is an historical challenge we continue to feel acutely. As a system we have never recovered from the drain of professional intervention skills that were drawn into the ICF/MRs to conduct endless assessments. We have not yet developed meaningful, flexible

mechanisms embedded in the community services system nor sufficient resources for intervening with behavior, allied therapies or medical needs.

We continue to admit individuals to developmental centers because of emergency needs that could be addressed in the community if we would create the capacity. In continuing to do this we fail individuals and families and perpetuate an institutional model-neither of which is acceptable or viable.

The Division of Developmental Disabilities came into being in 1985. State law changed the name of the Division from Mental Retardation to DD and adopted the federal definition of developmental disabilities.

At that time and since, functional assessment for determining eligibility for Divisional services has continued to be a gnawing policy and practice issue. People with disabilities other than cognitive impairments continue to experience difficulty in gaining eligibility, contending that the intake process remains heavily weighted toward an IQ score and mental retardation as a defining condition.

The movement of the system from a mental retardation agency to a developmental disabilities agency also illustrates the difficulty in estimating or predicting service demand at a time of innovation. The initial thinking, in which Elizabeth Boggs was very involved, projected that an additional 450 people with disabilities other than mental retardation would

apply for services within the first year, and the same number in subsequent years. More than 450 applied in the first month, overwhelming a system that, to begin with, was stretched. Once access to DDD services became a reality for some individuals and families the demand grew geometrically.

Demand for service is typically projected upon what people request and what people request is typically a function of what they know and what they see. The field of dreams phenomena, “if you build it they will come” seems to be a more accurate predictor of service demands. It also reminds us of the importance when trying to innovate, of giving people access to palpable demonstrations and information to dream about.

As we grapple with the task of creating public policy that addresses individual’s needs and desires with love and information, it is striking how many contrary examples we have. Though the federal ICFs/MR program, through its fiscal resources and its standards, has been and is still so central in structuring services at the state level is, it is also in many ways, a glaring example of public policy that is not based on love and information. Elizabeth Boggs in the book, *Parents Speak Out: Growing with a Handicapped Child* (1979), mentions the ICF/MR program as the only policy that she worked on that had any direct benefit for her son David. Despite our ongoing discomfort as a field, that ICF/MR as a Medicaid program has both “medicalized” disability and reinforced institutional models, the existence of these federal fiscal resources to match state dollars continues to be essential in improving services for people.

Initially, in many states, these dollars and requirements got people off mats on floors, into clothing and some activity. Personal living space increased and environmental safety issues have been addressed.

I spent a portion of a summer in the 1970s at the sweltering, non air-conditioned Western State School and Hospital outside of Pittsburgh, training people about these new ICF/MR regulations. I vividly remember the sense of excitement and possibility that we had federal regulations and resources that embraced the developmental model. That regulations recognized that all people have the capacity to grow and learn and that development is a result of the interaction of individuals with their environment.

Instead of seeing the full promise of these hopes what we have seen in New Jersey and around the country may be at best the letter of compliance. Compliance, although it brings funds that the system could not run without, lacks the essential spirit of what we want in our own lives and in the lives of the individuals we serve. As an expert witness in the suit against the Mansfield Training School in Connecticut in the early 1980s, I saw rows and rows of loose leaf program notebooks in chart racks, neat, detailed and holding nothing of consequence for those whose names were on the covers. As David Boggs' guardian I would sit through his annual Individual Habilitation Plan (IHP) meeting. Upwards of 12 dedicated, well meaning people presented evaluations and revised goals, such as increasing eye contact for an additional five seconds. While this meeting was going on, David and his colleagues

spent most of their time on the other side of the wall without meaningful activity. How much better would it have been to take that time and energy away from the pursuit of paper compliance, annual evaluations, isolated goal setting and perfunctory meetings, and put it toward human interaction?

To craft loving public policy we need to begin with the person, to stay with the person and remain with the person.

Person-centered-approaches have been at the heart of our work at The Boggs Center over the past 20 years. Individual planning techniques are an essential foundation, but this direction encompasses a broader restructuring of all services and supports from community living to employment, congregational supports, health care and education. From person-centered planning, as reflected in the Division of Developmental Disabilities' embrace and increasingly widespread use of Essential Life Style Planning, to having utilized a person-centered approach in the closing of North Princeton Developmental Center, and to Self-Directed Services, person-centered approaches are becoming the new paradigm for services in New Jersey. We are also beginning to see some person-centered changes federally through CMS' Independence Plus template as a Home and Community Based Services Waiver option.

In NJ's earlier deinstitutionalization efforts, the selection process for who could move to the community was based on the severity of the individual's disabilities. Initially, only people

with mild mental retardation were thought to be able or “ready” to live in the community. Eventually people with moderate mental retardation got to be able or “ready”. The American Association on Mental retardation, AAMR, in its classification manuals used to list the ceiling of abilities of individuals at particular ages and functional levels. With successive editions, these abilities increased. This progression (or changes in the assumptions about who could live in the community) did not reflect changes in the nature of disability, but rather changes in our abilities to intervene, teach and support. We now see limitations on who can live in the community as a matter of societal will and public policy, not disability or readiness.

Within this paradigm, supports available to the individual determine functioning. The intensity and extent of support needs are separable from where they are delivered.

Individual’s support needs vary in different areas. If we embrace this view, we clarify that all individuals can live in the community.

Embracing person centered approaches and the concept of supports begins to shape public policy that reflects what we value and want in our own lives-public policy based on love and information. Yet, we still struggle with exclusion and limited vision and views across systems: from education, to work, and to community living and participation. New Jersey, in many areas, remains a highly segregated state.



The shift to self-directed services in the Division of Developmental Disabilities initially through the Self-Determination initiative, now through Real Life Choices, and also in the Transition from School to Adult Life, can be seen as a collection of loving acts. This shift expresses a valuing of individuals and their families, and views people with trust and respect rather than paternalism or condescension. This shift represents policy that brings us back to personal life- trying to build or at least not get in the way of, that which we value in all of our lives. This shift, if implemented in a culturally competent way allows for a more typical life trajectory for families living with disability. It can support movement to independent adulthood for the person with the disability and room for parents to move through the later stages of adulthood, not always as caregivers of their children. Parents could enjoy the fruits of generativity and possibly retire to a different pace of later life. Demographically we know that at some point they will probably also be caregivers for their own parents.

We have much work to do to so that life choices are made by adults with disabilities and not only by families. We need to permit and promote the voices of individuals.

For those with families, we need to guard against self-directed services being too overwhelming or more taxing than a family can or wishes to take on at this stage of their family life. We also have a strong moral responsibility to ensure that individuals can still have access to self-directed supports if they do not have families or whose families cannot participate.

It is not sufficient for policy to chart a vision and direction without the supports, resources and the intentional realignment of structures and practice to make policy come to life for the benefit of people.

If we want the vision and direction of policy to be realized not mitigated, we need to find ways to ensure that there is adequate support for the individuals who work directly with people with disabilities. If we want to see classrooms that include all children, then we need to provide training and other resources to teachers and parents so that inclusion is viable and meaningful. If we want people with disabilities to have connections and occupations, to live and participate in their communities then we need to assist direct support professionals in achieving skills. We need to develop caregiving as a socially validated profession. How can we expect a community direct support worker with two children of her own to assist people with disabilities in achieving social justice, when the starting salary for her job keeps her and her family at or below the poverty level? Where is the equity in limiting options for community living for people with developmental disabilities because we have misframed the debate as community living vs. preserving jobs in institutions?

We need to ensure information if public policy is to be loving and viable. Families need to know where they stand with the service delivery system, what their options are and who is available to walk along with them in their journey.

The process of self-direction and making choices is, for all of us, both developmental and learned. People with developmental disabilities need information and support from early

childhood on to develop and utilize these life skills. If people with disabilities and their families are going to exercise self-direction we need to support people in their dreams with information about possibilities and strategies.

Participants in Boggs Center training programs often express a palpable hunger for up to date information and an understanding of policy and trends. If we expect people who work in the field to function by rote, without information, how can we be surprised if they then cannot or do not feel either equipped or inclined to empower people with disabilities and their families? The beauty of the developmental model, mentioned earlier, is that we are all capable of learning over the lifespan. Our collective challenge, and I think The Boggs Center has a particularly affirmative responsibility in this, is to ensure that we generate, share and utilize information from which we can and do learn.

Bobby Silverstein, Senator Harkin's staff director in the passage of the ADA, the nurturer of the DD Act and the legislative guardian angel of early intervention, carried forth the simple and powerful message during the fight to secure passage of the ADA: 'the disability community must stay together; the disability community must stay together'. That continues to apply to all of us, even more so in today's fiscal, political and social climate. We need to build alliances with the larger society and we need to hold each other dear in the process, because it is morally right and strategically essential. It could serve the less progressive forces in the society well if we dissipated our energy in disagreeing among ourselves. We

must find ways to bring our message to the larger community that is both clear but does not reduce our cause to single issues or simple fixes.

As we work to create and make real public policy based on love and information we must be continuously reflective and vigilant, lest we reinvent absolutes as we have in the past.

Twenty years from now, will our successors be gathered in a similar, perhaps by then, virtual celebration, still struggling with public policy that does not well serve people with disabilities and their families?

With where we are, who we are and what we know, I propose some hedges against that possibility. We can act with love and information if we create public policy that listens to people; that sees and respects people with disabilities in the context of their families' and communities and also creates capacity in communities. We need policy that sees itself as instrumental not an end in itself, policy that honors the larger social contract and reciprocity between individuals and individuals and the society.

We need to create public policy that recognizes that what is important to all of us is both shared, and at the same time, highly specific and highly personal. Public policy that, in its content and results, creates services, supports and enables lives, that are, in the wonderful words of the late Commissioner Ann Klein, "good enough for me".

Let us try to 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 twenty years.

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### Acknowledgement:

When I was writing this, having already entitled it “Love and Public Policy”, I had the opportunity to hear the Graduation Speech delivered by Nancy Starmer, the Head of George School, to the Class of 2003. She shared the concept of “Love and Information” which Paul Lacey of Earlham College had introduced to the George School community in October 2002. These terms, from the writings of William Penn, captured the spirit of what I was trying to say. My thanks to Nancy Starmer and Paul Lacey for sharing these powerful and embracing thoughts.