



**Cerebral Palsy Associations  
of New York State**

*Real people. Realizing potential.*

**TESTIMONY SUBMITTED TO  
THE NEW YORK STATE ASSEMBLY  
STANDING COMMITTEE ON MENTAL HEALTH AND  
DEVELOPMENTAL DISABILITIES**

**Hearing on  
The Adequacy of Supports and Services for Individuals with Developmental  
Disabilities**

*Presented by*  
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Cerebral Palsy Associations of New York State  
Board Member

**October 20, 2015**

Good Afternoon Assemblymember Gunther and members of the Assembly Mental Health and Developmental Disabilities Committee. Thank you for inviting me here today. My name is Brian McLane. I spent most of my adult life in the world of government and politics and it is good to be back.

My appearance before you today is to lend support to the grave concerns that Cerebral Palsy Associations of New York State (CP of NYS) and the thousands of families share about the erosion of funding that allows individuals with disabilities to stay in non-institutional settings and to live independent lives in their communities.

I am also concerned about the growing trend in the development of new programs that sees the problem as managing the care of individuals, rather than developing opportunities for individuals to live in their community.

CP of NYS is providing written testimony on their concerns including: years of funding cuts and the lack of development of supports and services for individuals with developmental disabilities; workforce sustainability and wage increases for direct service professionals, particularly in light of the \$15 minimum wage for fast food workers; the transformation of ICFs to IRA's without any funding; and the move to managed care.

Today I would like to discuss with you briefly why these issues are important.

On September 11, I will celebrate my 70th birthday. This is a pretty amazing event given that my life expectancy was not to exceed 50. Among other things, this celebration means that I have been alive in the 1940s, 50s, 60s, 70s, 80s, 90s, and 15 years into the new millennium.

I am a person with a developmental disability. Every day of my life I have been dependent on people and machines. Every day of my life I have needed assistance in dressing, bathing, toileting, transferring, and getting around. I speak to you today as someone who knows what it means to have dependencies.

My parents had a vision. Before there were laws, they had the inspiration that anyone who has a vision of a way to make things better can make that vision a reality – if they have the courage and perseverance to see it through.

My parents wanted to create a better life, not only for their son, but also for other children with disabilities. They refused to accept what was, and worked instead toward what could be.

When I was born 69 years ago, people with disabilities seldom had such rights. Parents were urged to put their children into institutions, to spend their lives as perpetual dependents, shut away from the rest of society. My parents and others like them said “NO!” They joined together to form organizations like United Cerebral Palsy: organizations to support them as they raised us at home and as a part of our communities; organizations that assisted them in advocating for a share of the community's resources and attention.

The result of the involvement of my parents – and others like them – is that I, and children like me, grew up at home and not in institutions. Our parents began the process of opening doors to educational opportunities for their children. They prepared us for a life of work and service to our community.

**It is hard to believe, but it wasn't until 1972 that individuals with disabilities were guaranteed a free public education under the law. However, in some quarters of our government, and society, we are once again debating if this is a good use of our resources.**

I am product of the 60s... a time when leaders had a vision and challenged all of us to look at traditional and institutionalized ways of doing business. We were taught to ask, "Is there a better way?"

**Expectations that we set for ourselves – expectations that others set for us – have everything to do with what we are able to accomplish in life. You are only limited by your imagination – your own will – your own desires.** If you have no expectations, then outcomes are forgone conclusions. Your deliberations could very well set the boundaries of these expectations.

Today I challenge you to look beyond what is comfortable, what is expected, and what you know. I fear we now have a generation of families and individuals with disabilities who do not know what life was like without the many rights services and programs that exist to support our families today.

We as a society moved away from the belief that the best way to deal with issues relating to individuals with disabilities is to put them in institutional settings or into segregated separate environments.

**However, in some quarters of our government, and society, we are once again debating if this is a good use of our resources.**

**In some quarters of our government, both state and federal, we are questioning whether funding for such programs as Medicare, Medicaid, Medicaid Buy-In, Self-Directed care, Housing, special-education, vocational rehabilitation and other supports and services should be continued, and if so, to what extent?**

**The discussions in Albany and Washington center around money. But in reality, the debate is really about what our society values. I know the wealth of this country lies in the private sector, not the government. For those of us that care, we must turn our energy; we must turn our advocacy; we must build a constituency for our agenda amongst those who have the ability to assist us in achieving our goals for our family members.**

**While most believe it is about money, it is really about "what is it as a society that we value?" As a society, do we have any obligation to each other? There is a fear in this country that both the public and private sector have failed to come together to protect the American dream.**

**Our goals for our families, for our children, for our children with disabilities are part of that dream.**

**Indeed the torch has been passed to a new generation. This generation must never take for granted the gains we have made.**

Bobby Kennedy once said, “There are those who look at things the way they are and ask ‘*WHY*’...I dream of things that never were and ask ‘*WHY NOT?*’”

For the people in this room you must always ask yourself---“WHY NOT!”

As always, thank you for listening.