

To: Sharon Lewis
Commissioner Administration on Developmental Disabilities

From: Patricia L. Maichle
Director Delaware Developmental Disabilities Council

Date: October 18, 2010

RE: Envisioning the Future 2010: 20 Years After ADA – How equal are we?

Thank you for allowing me to provide this testimony on behalf of the Delaware Developmental Disabilities Council.

Every day, someone communicates to us an experience of inequity, unfairness, injustice, denied access, environmental barriers, and failures of a system meant to equalize people's lives; whether it be in housing, health care, dental care, long term care, employment, technology, family support, education, the practice of religion, recreation, safety and freedom from abuse, or any other aspect of every day life. Although, as quoted by Larry Henderson, "the ADA, so far, has elevated us to a level of minority", it is time for the ADA and other law to take us to equal.

A few examples in the recent past will illustrate the point. During an effort to educate and advocate for a Code change in Delaware to require automatic doors for all new commercial construction, a commercial real estate lobbyist expressed concern for the cost of such a requirement and asked the sponsoring State Representative "why people with disabilities couldn't just use the back door." In a meeting with a school district for a young person in special education who was interested in post school employment, the district employment specialist asked the parents of this young woman "why do we need to sample jobs for transition? Won't she live in a group home and live off of the state?" Delaware still has sterilization language in the state Code for people with developmental disabilities and mental illness (De.Code, Title 16, Chapter 57, §5701 – 5715 <http://delcode.delaware.gov/title16/c057/index.shtml>.)

Envisioning the future and highlighting the most important contributing factors to ensure that adults with developmental disabilities achieve equality of opportunity, independent living, economic self-sufficiency, and full participation as valued members of inclusive, integrated communities, we must prioritize the most critical issue to be addressed in the near future. In addition, we must understand and respect that the advocacy and work that

has been done in the past that has encouraged and allowed today's generations of young people with disabilities to grow up at home with their families and to go to schools with all of the other kids in the community has also grown a generation of young adults who will not accept or go gently to any place that segregates and separates them from those other young adults who are in their communities. They will not tolerate inequality.

An overarching critical issue is the basic premise of self-determination that must exist in every other issue for each person with a disability. Every person must be able to expect dignity and respect and be able to make informed choices as adults. We have spent billions of dollars through the federal IDEA to educate our children with disabilities to be independent, to think for themselves, to be employed, to be consumers of goods, to pay for their own insurance, to vote, to be taxpayers, to live like everyone else. Now, we must let them do just that.

A second critical issue for adults that, if achieved, can allow for many to move closer to independent living and economic self-sufficiency would be employment. Barriers such as the "Order of Selection" that some states enlist, must be removed permanently. No other federal program in states, such as food stamps or Medicaid, allow for a wait list. Why is it okay for employment of people with disabilities? Business leaders should be employed to expect a good worker when they look at an applicant with a disability. We must get out of our disability box and use the business knowledge and techniques that exist for every other worker and use this to our advantage. We must educate good workers and we must employ good workers in all fields worldwide. When was the last time a person with a disability sampled a job in Europe or Asia? Do they have the skills to accomplish that?

A third critical issue is family support that is individualized to meet the needs of each family and to allow people to live how and where they choose. This has been a problem since people started rejecting institutionalization 50 years ago. Families want to stay together and, yet, the bias in the laws and programs is to provide unequal funding for institutions at a rate that far outweighs the support that families even dream of to provide what is needed for people with developmental disabilities. Families need to be able to live, recreate, work, practice religion, to move about in their communities and in our world in a manner that is respectful, free of barriers, affordable, and safe. How can they do that when something as simple as parents completing a full day at work is thwarted by a care system that is only open from 9 – 3?

During the effort to plan for the future for people with developmental disabilities and to bring equality to our communities, we must allow for people with developmental disabilities to lead us in the direction they choose to go. We must listen to them honestly. We must hear them when they communicate. And, we must act to help them fulfill their vision for their future. We have given them the tools to empower them, now we must let them live. The Delaware Developmental Disabilities Council is eager to be part of this future.

Thank you for your time and attention.

