Testimony of Susan J. Willis

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Regarding H.B. 166

Senate Finance Subcommittee on Health and Medicaid

Good morning Chair Hackett and members of the subcommittee. Thank you for the opportunity of speaking to you from an advocates' perspective on a part of House Bill 166.

I am Sue Willis, living in my hometown of Columbus for 74 years. I was born with brittle bone disease, causing me to have more than 100 hospital stays, heavy casts, and braces. I walked with crutches until about 16 years ago when I transferred to a power chair. Regardless of these disability related parts of my life, I've lived as a very independent person (just ask my parents when I told them I was moving to Denver).

I received Bachelor's and Master's degrees in Communication and Design from The Ohio State University – I must add this was before the Americans with Disabilities Act, and trudging across the campus during winter quarter was no fun. Following college I worked for a publications firm, followed by four years in Denver as Art Director of an educational publisher.

I returned home to set up a photo/design business with a good friend and professional photographer. We became successful providing training programs and advertising materials to central Ohio companies. One of these was the Ohio Rehabilitation Services Commission (RSC). Now called OOD. RSC opened many doors to prospective customers, including writing for grants. In 1992 I received a large federal grant awarded by the Ohio Developmental Disabilities Council (ODDC). From that time on, I opened and operated the AXIS Center for Public Awareness of People with Disabilities. Axis created public awareness materials, presentations, conferences, and perhaps most note-worthy, a statewide newsletter that people today still ask me about.

I mentioned earlier that I am a very independent person, something that I believe every person with a disability should have an opportunity to become. Achieving an education, owning a home, buying a car with hand-controls and a ramp, working, paying your own bills, and being a part of the community helped me become independent. I look back at all the years I went to school and began working--when I was doing everything I could without highlighting my disability. In fact I did what I could to avoid being labeled “disabled.”

It wasn’t until I began my work with ODDC that I found my “voice.” I realized my disability wasn’t something to be ashamed of. Instead, I could use my voice to help the more than 20% of Americans gain their independence--and to engage their families, employers, schools, and the public at large about “my population.”

Not only do I continue to produce products for and about people with disabilities, I have joined multiple organizations that assist individuals with disabilities achieve lives of their choice. I currently belong to: Ohio Developmental Disabilities Council, Ohio Olmstead Task Force, Columbus Advisory Committee on Disability Issues, Twigs of Nationwide Children’s Hospital. I regularly attend and participate in events of: Ohio Self Determination Association, Ohio Association of County Boards, OSU Nisonger Advisory Council, Statewide Independent Living Council, Youth Leadership Forum, and others.

In 2012, I was asked to join the Board of Directors of Disability Rights Ohio (DRO). This is the year when DRO became a non-profit corporation, replacing Ohio Legal Rights, which was a state agency. The mission of DRO is to advocate for the human, civil and legal rights of people with disabilities in Ohio. This mission is something that I strongly believe in.

This is also the mission that will be affected **negatively** by the provision of H.B.166 section 5123.603. I assume you all are familiar with, or understand all the technicalities of this section. I will speak to you about my understanding of the section and how it may affect me, and other Ohioans with all types of disabilities.

DRO's Board has 13 members, half of which are people with different types of disabilities. Members are from different parts of the state and have various racial and cultural backgrounds. We all speak and act independently.

As a member of DRO for seven years, I have learned much about what the organization does—significantly more than what most Ohioans understand. I've seen first-hand how DRO can help individuals and their families.

The board has heard about abuse and neglect of people of all ages from staff who have made visits to various facilities. Most of us do not know or ever think about the extreme conditions that DRO has found. No one, regardless of their disability, often a mental disability, should live and endure such terrible conditions. But who else has the authority to enter these environments, unannounced, and see these situations so DRO can begin to clean up the atrocities.

While much of DRO's work revolves around abuse and neglect, it looks into many other situations. Employment, one of my most important issues, is frequently looked into. How many places "employ" individuals with disabilities for less than minimum wage, even though they may be doing the same job as the people next to them. Too often, the families or others, think it's ok just for the person to be out at a job making money. DRO is making sure that people with disabilities can start earning livable wages.

Another of my key issues is education. DRO looks into many calls from parents who don't understand the IEP process or why their children are not being taught alongside other youth, and why are they not using appropriate assistive technology. Frequently, staff can handle these calls by providing information or making one visit to the school. Many problems DRO hears can be settled or worked out by having one meeting to explain rules and regulations to both parties.

Adults with disabilities and families of youth with disabilities are some of the most low income and cannot think of hiring lawyers to assist with their problems. When people call DRO with a concern, they are always listened to. Their concerns are forwarded to a team leader who evaluates their situation and determines whether DRO can assist them or whether they can be referred to another source. Because DRO's funding is allotted by federal grants for certain amounts under specific categories, it is not possible to serve everyone who calls, but staff always tries to give people alternatives. We stretch our money as far as we can.

As board members, we are entrusted to hear and discuss issues that DRO is working on. We in turn, with all our varied backgrounds, can provide helpful information and strategies. In addition, we approve fiscal statements and audits, we participate in site monitoring, and help develop strategic priorities.

I cannot begin to describe all the reasons why lawyers and the court systems can take so long to resolve issues. However, I know that several of DRO's major cases have taken years to come to a solution. If the proposed provision is passed, it will lengthen or perhaps dissolve cases that are currently being heard. A new entity cannot step in and know how to pick up where DRO has been working for so long.

Lastly in my comments today, I don’t understand how an issue designated by the federal government to protect and advocate for people with disabilities in Ohio can be put into a budget bill. I believe a budget bill includes numbers and finances not personal lives.

I believe we should continue to follow current federal law and not interrupt the work being done to improve the lives of all Ohioans with disabilities.

Thank you for your attention. I’ll be happy to answer any questions.

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