Testimony of Walter Glomb Executive Director of the Connecticut Council on Developmental Disabilities to the Informational Forum on Access To Health Care September 13, 2023

Good afternoon everyone.

My name is Walter Glomb. I am the Executive Director of the Connecticut Council on Developmental Disabilities. I am also a parent of an adult who lives with developmental disabilities.

The Council is a division of state government that is entirely funded by the federal Administration for Community Living for the purpose of helping Connecticut to improve its system of community-based services and supports that enable individuals with developmental disabilities to live in the home and community of their choice.

This includes access to health care. The Americans with Disabilities Act requires that health care entities provide full and equal access for people with disabilities.

I am here today to explain that physical access to medical diagnostic equipment is just one of many challenges faced by individuals with developmental disabilities in accessing health care.

Developmental disabilities are lifelong impairments that result in substantial functional limitations in three or more areas of major life activity and require lifelong services and supports. Developmental disabilities may include intellectual disabilities, severe behaviors, autism, anxiety, schizophrenia, physical impairments, visual impairments, or hearing impairments.

Please understand that developmental disabilities are not conditions to be fixed. Developmental disabilities are conditions to be accepted and accommodated in our communities.

In 1981 the Council received a grant from the federal Center for Disease Control to improve access to the COVID-19 vaccine by people who live with developmental disabilities in Connecticut. Our primary concern was individuals with intellectual disabilities, severe behaviors, autism, and psychiatric disabilities.

Through that work we learned that many individuals had been denied necessary accommodations for vaccination at major health care providers.

We would ask these individuals, "How do you normally get your vaccines?" and, from many, the answer was, "We don't." Thus, we began to learn that many people with developmental disabilities are not receiving essential primary care.

In 1981, in collaboration with the Town of Vernon, the Council set up a special clinic to provide vaccinations to individuals with developmental disabilities where we learned that many individuals with developmental disabilities require more intense communication with a provider prior to a visit, more time and space, a sensory friendly environment, and, in some cases, staff certified in physical management techniques.

Furthermore, as a parent of an individual with a developmental disability and as director of the Council I continue to see barriers to health care.

Though our information is largely anecdotal, the national research by Dr. Iezzoni and her colleagues, and surveys by the University Center for Excellence in Developmental Disabilities here in Connecticut, support our concerns that many individuals with developmental disabilities are not receiving necessary accommodations for essential primary care.

Beginning next week on September 19, the Council will begin hosting a series of speakers to educate policy makers about healthcare challenges facing people with developmental disabilities.

We will share national research, local experiences, and initiatives in other states.

We hope that our program will begin a broader discussion about ways to provide necessary accommodations for essential primary care.

Thank you.