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**WRITTEN TESTIMONY OF  
QUALITY TRUST FOR INDIVIDUALS WITH  
DISABILITIES, INC.**

**Before the Council of the District of Columbia, Committee on Health and Human Services**

**In Opposition to Bill 21-0038 (“Death with Dignity Act of 2015”)**

**July 24, 2015**

Quality Trust for Individuals with Disabilities (Quality Trust) joins the D.C. and National Centers on Independent Living, the Autistic Self Advocacy Network, The Arc, and other local and national disability rights organizations in opposing Bill 21-0038.

Quality Trust is an independent, non-profit advocacy organization in D.C. that has been advancing the interests of people with intellectual and developmental disabilities (IDD) since 2001. We monitor the quality of services provided and advocate for whatever changes or improvements are needed to enable people with IDD to live full, healthy, and meaningful lives.

For more than a decade, Quality Trust has been addressing concerns about capacity and consent in the District and beyond, through education and training, individual advocacy, resource development, and legislative change. We work closely with adults with IDD, their families, their attorneys, D.C. governmental agencies, and others in their circle of support, so that people with IDD can build their skills for decision-making and make their own important life decisions to the maximum extent possible, including those pertaining to end-of-life planning. To this end, in October 2013, we launched the Jenny Hatch Justice Project, an integrated, multi-faceted resource and outreach center dedicated to advancing people with disabilities’ right to make their own choices and determine their own path and direction in life.<sup>1</sup>

Quality Trust supports the Right to Make Choices as an essential part of dignity and respect for all people. However, in order for us to know that a person’s choice is a truly voluntary and informed one, we must be assured that he or she is free from duress and coercion, including those pressures that can be created by society-at-large, based on misconceptions about what it means to live with a disability. As such, the D.C. Council’s decision about whether or not to legalize physician assisted suicide – by definition, an irreversible act that ends a person’s life – must not be made without a full appreciation of how it could negatively impact populations, including people with IDD, who have historically faced discrimination in the medical field and are at a higher risk of abuse, isolation, and exploitation. It is through this lens that we want to share our deep concerns regarding Bill 21-0038.

### ***Discrimination & Misconception Surrounding “Quality of Life”***

Studies and legal research show evidence that people with disabilities face discrimination based on low opinions within the medical profession about their perceived quality of life.<sup>ii</sup> In our work with people with IDD, we have seen this first-hand in D.C.

For example, we are aware of a case in which a doctor recommended hospice for a person, simply because the person had cerebral palsy (cp). The hospital discharge diagnosis literally read “terminal cp”. Yet cerebral palsy is not a disease. It is a life-long neurological condition, which primarily causes physical impairments involving limitation or loss of function and mobility.<sup>iii</sup> While a person with cerebral palsy may need assistive technology and supports to help with daily activities and navigate life, the diagnosis, in and of itself, is not a death sentence.

This illustrative example brings into sharp relief how doctors’ devaluation of the quality-of-life of people with IDD can lead to erroneous conclusions about what constitutes a “terminal disease.” Of course, those kinds of biases become all the more dangerous if they could lead to the prescription of life-ending drugs.

In the few states that have legalized physician assisted suicide, we have not found quality data on the experience of people with IDD. In light of the long history of societal marginalization of this population, this kind of data is critical to evaluate the full ramifications of such laws. We urge the D.C. Council not to be an early adopter of legislation like B21-0038 without thoroughly assessing whether it will bring with it unintended consequences.

### ***Lack of Strong Safeguards***

B21-0038 does not have robust safeguards to ensure people’s lives are not ended without their informed consent, and thus creates the potential for abuse, particularly in the case of people with IDD.

This legislation does not require mandatory mental health screenings, instead leaving it to the prescribing doctor’s discretion. In 2013, only two of the 71 Oregonians who died from physician-assisted suicide were even referred for formal psychiatric or psychological evaluation.<sup>iv</sup> People, including those with IDD, can experience mental health issues, including depression, in times of stress, when facing a serious diagnosis, or when experience declining health or mobility. Advance mental health screenings should be required to ensure a decision – literally, about life and death – is a truly informed one.

Moreover, the legislation does not include safeguards to ensure that the lethal medications are taken voluntarily after they are prescribed. As a result, no one can verify that the person actually taking the medication is doing so of his or her own free will. In this way, rather than effectuating “choice,” signing a request for lethal medication could well translate into a loss of personal control and abuse, particularly for those who rely on the support of caregivers.

### ***Focus on High Quality Community Supports to Destigmatize Disability***

At the hearing on this legislation, many supporters raised concerns about the “indignity” of declining health and the need to depend on someone else for help. In Oregon, 93% of those who died from physician-assisted suicide in 2013 cited “loss of autonomy,” as a motivation, while less than 28% cited concerns about pain control.<sup>v</sup>

This message speaks loudly about the persistent societal stigma towards a person having a disability – even one acquired through illness. We fear this stigma will only be reinforced if this legislation is enacted. The District should instead be focusing its efforts on ensuring that all people have access to high quality in-home supports, palliative care, mental health services, durable medical equipment, and other assistive technology, so that they can retain as much control over their lives as possible.

Thank you very much for hearing our concerns. If you have any questions or wish to discuss these issues further, please do not hesitate to call me at 202-459-4004 or [MWhitlatch@DCQualityTrust.Org](mailto:MWhitlatch@DCQualityTrust.Org).

**Respectfully submitted by:**

**Morgan K. Whitlatch  
Senior Attorney**

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<sup>i</sup> See Jenny Hatch Justice Project, <http://www.JennyHatchJusticeProject.org>

<sup>ii</sup> See, e.g., Nancy K. Stade, *The Use of Quality-of-Life Measures to Ration Health Care: Reviving a Rejected Proposal*, 93 Colum. L. Rev. 1985 (Dec. 1993); Elizabeth F. Emens, *Framing Disability*, 2012 U. Ill. L. Rev. 1383 (2012)

<sup>iii</sup> See <http://cerebralpalsy.org/about-cerebral-palsy/definition/>

<sup>iv</sup> See <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>

<sup>v</sup> See *id.*