



Testimony of Stephanie Woodward on behalf of ADAPT
in Opposition to Assisted Suicide
May 3, 2018

Good afternoon and thank you for the opportunity to testify today.

My name is Stephanie Woodward and I am an organizer with ADAPT. ADAPT is a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom. ADAPT is comprised of disabled people who know firsthand what it's like to have doctors, family, friends, and strangers tell us that our lives are not worth living. ADAPT is strongly opposed to the legalization of assisted suicide in New York State.

Though ADAPT has been fighting for the lives and liberty of disabled people for over 35 years, with more than 40 chapters throughout the United States – including four in New York State – ADAPT has most recently gained media attention this past summer for fighting to save Medicaid when over \$800 billion Medicaid dollars were at risk in the many proposed bills to repeal the Affordable Care Act. Many disabled, elderly, and ill people rely on Medicaid to live, and especially to live in the community instead of being forced into nursing facilities or other institutions. We regularly chant our mantras: “Free Our People” and “Our Homes Not Nursing Homes” both in reference to the forced institutionalization of elderly, disabled, and ill people.

There was a time when New York State recognized our right to live in the community. In fact, New York’s 2013 Olmstead Plan reads: “Building on the Care Management for All initiative, reforms in the 2012-2013 budget removed the financial incentives that may have encouraged nursing home placement. Previously, nursing home costs were “carved out” of managed care rates and were instead covered by the state. This policy had the potential to encourage managed care plans to pressure high-cost people served in community-based settings to enter nursing homes.”¹

Unfortunately, just over a month ago, Governor Cuomo and the New York State legislature turned their backs on our community by including a 90 day nursing home carve out, thus causing the exact harm the State recognized this would do – forcing people with the highest needs into nursing homes.

Why does this matter? What does this have to do with assisted suicide?

Derek Humphrey, the founder of the Hemlock Society – better known today as Compassion and Choices – aptly stated “Surveys have consistently found that most people would rather continue living at home rather than in a nursing home. What has not been known until recently,

¹Report and Recommendations of the Olmstead Cabinet, page 14, available at <https://www.governor.ny.gov/sites/governor.ny.gov/files/archive/assets/documents/olmstead-cabinet-report101013.pdf>

however, is that the aversion to ‘such a facility is so strong that 30% of those surveyed said they would rather die than live permanently in a nursing home.’” Well, on that point only, ADAPT agrees wholeheartedly with Mr. Humphrey’s statement. However, Mr. Humphrey came to the following conclusion: “Why do we, as a nation, not allow these people to die, if they have no alternative to a nursing home existence and this is what they want? Their lives would conclude with dignity and self-respect, and one measure of cost containment would be in place.”²

This conclusion wrongly assumes that the only option for elderly, ill, and disabled people is to choose between nursing homes or death. There is no discussion of the need for community based services so that people who need services and supports can receive them in their own homes in the community. If a person would rather die than live in a nursing home, the answer must be to provide appropriate services and supports to allow people to live in the community so they never have to go to a nursing home. The answer must be to help older New Yorkers to age in place. The answer is not to let people die.

ADAPT is appalled by Humphrey’s answer, and yet, this is exactly what New York State is proposing. New York State will not give us the services and supports we need to live in the community, but will give us assisted suicide and call it a choice. New York State, in its own words, has set up a healthcare system to force us into nursing homes, even though anecdotal evidence shows that people would rather die than go to a nursing home, but you tell us that assisted suicide is a choice. If New York State does not give us the choice to live – a real choice to live – how can New York possibly say that it’s a choice to die?

In a state that is not willing support disabled, ill, and elderly people in living our lives, physician assisted suicide becomes economically coercive. New York has consistently chosen the cheaper option for disabled people at every turn. Assisted suicide offers the cheapest option of them all. As Derek Humphrey pointed out in his conclusion, assisted suicide is a form of “cost containment.” It gives disabled New Yorkers a choice between lives without the supports and services we need or death. This, combined with social coercion and rising elder abuse further coerces our vulnerable elders into thinking assisted suicide is the only choice – and therefore not a choice at all, but rather, a duty to die.

In addition to the ugly choice this bill foists upon disabled and older New Yorkers, it has the potential to worsen the already problematic issue of higher rates of violence and abuse faced by our community. Every year on March 1st ADAPT and other disability led organizations mark the Disability Day of Mourning by reading the names of disabled people who have been murdered by family members and caregivers. It is a list that grows longer each year. This legislation, which is essentially an immunity statute, would offer a repercussion free path to committing these crimes and would reinforce the dangerous idea that disabled and older New Yorkers are a burden whose lives are not worth living.

² D. Humphrey and M. Clement, *Freedom to Die: People, Politics, and the Right-to-Die Movement* (St. Martin’s Press 1998).

For example, in January of this year, a woman named Ann Bell celebrated her 101st birthday. Ann was born in 1917, lived through the great depression, and raised two children, five grandchildren, seven great grandchildren, and three great great grandchildren so far. I have known her for my entire 30 years of living because she is my great grandmother. I call her Mimi. I checked and she's okay with you calling her Mimi too.

Mimi has lived in Rochester, NY her entire life. Mimi took care of her mother as her mother aged, just as she took care of her children and their children and their children. In 1994 Mimi held her mother when she died, and in 2008 she held her daughter – my grandmother – as she died of lung cancer. Mimi stayed with me in the hospital after all of my surgeries as a child. In my family Mimi has loved, nurtured, and raised us all.

In January, we celebrated Mimi's 101st birthday at my house with sandwiches and coffee because, according to Mimi, we shouldn't make a big fuss about turning 101 because it isn't a big deal. To be fair, her mother lived to be 110, so Mimi has a different frame of reference than the rest of us. After we had sandwiches, we brought out the cupcakes and sang her Happy Birthday. When the singing ended, I turned on the video recorder on my cell phone and asked Mimi how it felt to be 101 and if she was going to make it to 110. She said no and when I asked her why not her response was "I don't want to – too much work for people." But when I asked her how her first 101 years were, she said "good, so far."³

On her birthday, Mimi, who has, according to her, had a good 101 years of life so far, and who was surrounded by her loving and supportive family, said she does not want to live much longer – not because she's in pain – but because she thinks keeping her alive is too much work for other people.

Now I'm not saying my Mimi has any specific terminal diagnosis right now, but I am willing to bet if she stops any of her regular treatments, as a 101 year old woman she is likely to be considered terminal. It breaks my heart that my Mimi would want to stop living because she thinks her life is too much work for other people. It frightens me that I live in a world where feeling like a burden on others is one of the top five reasons people choose assisted suicide⁴. Not pain. Not unbearable physical suffering. People cannot get the services and supports they need to live happily in the community, so they feel like a burden to their loved ones and want to end their lives so as not to inconvenience others. Legalizing assisted suicide sanctions this idea.

Mimi is just one woman, I know. But how many Mimi's are in our state? How many incredible, elderly women will seek assisted suicide so as to not be an inconvenience to someone else?

³ Video of Ann Bell on her 101st Birthday, available at:

<https://www.instagram.com/p/BdqeIXJFpb/?taken-by=stepfunny426>

⁴ Oregon Death with Dignity Act 2017 Data Summary, page 10, available at

<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>

After all, society has raised women to not get in the way. Society tells us women to be nurturing and to care for others and to shrink ourselves to make room for other people. As a woman in 2018 I have been taught this, can you imagine what women who lived through the 1920's, 30's, and 40's were taught? This idea is so engrained in my Mimi that she does not want to live to the age that her mother lived because she does not want to cause work for other people. She is not the only woman who would be at risk of dying if assisted suicide was legalized because she is not the only woman who has been taught to accommodate others above all else.

ADAPT urges the Assembly Health Committee to recognize that our State does not give disabled, elderly, and ill people a real choice to live, and therefore, must not legalize assisted suicide as a so-called "choice" to die. We urge you not to pass this dangerous legislation, and instead, work to improve our healthcare system by offering disabled, elderly, and ill New Yorkers a real choice to live in the community with the supports and services we need.

Respectfully submitted,

Stephanie Woodward

Enclosed: Image of Mimi on her 101st birthday



Mimi on her 101st Birthday
January 2018
Rochester, NY