

# UNITED SPINAL<sub>NOW</sub>

## No Choice If System Is Broken

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**E**ach of us has struggled with either government- or insurance-provided healthcare. Most of us – if we are good self-advocates – get what we need, but not optimum care. The struggles are overwhelming, especially for those with stamina, pain or cognitive problems.

The battles waged by those who need personal care attendant services is perhaps the toughest. In these times of low unemployment and, for the most part, increasing wages (if only due to inflation), homecare workers are in short supply, and many Americans needing personal care services go without them or are institutionalized in nursing homes.

The choice to live in the community is illusory, if adequate support services are unavailable. The system is broken. The default (nursing home care) when personal care attendant service is not available, because the job is not attracting workers, is far more expensive and far less desirable for people with disabilities.

“Choice” is much in the news. Personal autonomy is the issue for those supporting abortion rights. Personal autonomy is put forward as the rationale for physician-assisted suicide, as well. It is a choice for the terminally ill, right? Wrong!

In the ten jurisdictions in which it is legal in the United States, the definition of terminal is “with or without intervention,” i.e., a diabetic or a quadriplegic, each of whom would die without medical intervention, is eligible if they can find a doctor to write the prescription, and unfortunately, they can.

The slippery slope of physician-assisted suicide has gotten even more treacherous in Canada. Canada doesn’t even pretend that their Medical Assistance in Dying (MAID) Law is for the terminally ill only.

Eligibility for MAID includes those who have a serious and incurable illness, disease or disability, as well as those with physical disabilities suffering psychological conditions that cannot be alleviated in a manner the person considers acceptable.

All of this means that people with disabilities who are depressed can get drugs to kill themselves from a government-sanctioned program.

Why discuss inadequate homecare and physician-assisted suicide in the same article? Winnipeg resident Sathya Kovak used the Canadian MAID Law to kill herself. She was 44. According to the *Manitoba Standard*, she made a carefully considered decision to die, because the difficulties she encountered with homecare made it unpalatable to continue living.

She wrote, “I could have had more time, if I had more help. There are not enough supports and services promoting quality of life and independence for those who are not healthy and able-bodied. There is desperate need for change... I felt like I had no choice but to end my life. Ultimately, it was not a genetic disease which took me out. It was the system.” She continued “Life does not end with less physical ability – it ends with less support.”

For some reason, making it easier to kill yourself if you have a disability is a goal of some in government. United Spinal Association members have told me repeatedly for decades that they were suicidal after injury.

Others struggle nobly to live in the community as independently as possible, and are constantly juggling homecare workers and having to sacrifice opportunities to work and socialize in order to maintain basic services.

For overwhelmed people with disabilities who are not receiving adequate care, or can’t find accessible housing, or are being denied appropriate equipment, the government-given “choice” of physician-assisted suicide is despicable.

How about alleviating pain, providing accessible housing and enough homecare, and modifying the benefits system so that work and accumulation of wealth are not inconsistent with the receipt of personal care?

Codifying the right to have a physician help you kill yourself if you are disabled is the ultimate in ableist legislative efforts.

If the disability is removed from the equation, what doctor would prescribe drugs to people who wanted to kill themselves? Add disability back in, and somehow suicide seems rational to both legislatures and cooperating physicians.