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Aid in living, not dying



Annapolis, MD-3/11/15-At the Miller Senate Building, O. J. Brigance, a former Ravens football player who has ALS, a neurodegenerative disease, waits to testify against a bill to legalize physician-assisted suicide. Seated next to him is a supporter of the bill, Catherine Weber with Maryland Action Team for Compassion & Choices. Algerina Perna/Baltimore Sun-#9354. (Algerina Perna / Baltimore Sun)

By **Samantha Crane**

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Around the country we have seen a concerted effort by special interest groups to promote the legalization of physician-assisted suicide, including **legislation introduced in Maryland**. Although these groups claim to be speaking for people with chronic illnesses and disabilities, no major nationwide disability rights groups support physician-assisted suicide. In fact, these laws make people with disabilities more vulnerable and reinforce the damaging perception that life with a disability is "undignified" and not worth living.

Although assisted suicide advocates claim that their legislation is about terminal illness and not disability, many of the arguments presented in favor of such physician-assisted-suicide legislation here and around the country assert a supposed "indignity" in needing help to eat, move, breathe or take medications. These arguments are rooted in a belief that it is better to die than to depend on others for assistance.

This belief is so pervasive that many people who become disabled find themselves struggling with suicidal thoughts. These thoughts may stem from the feeling that one is a burden on family members, fear of being placed in an institutional setting like a nursing home, or isolation as a result of lack of in-home supports. Moreover, people with disabilities are at heightened risk of abuse, isolation and exploitation.

Instead of addressing these significant risks, this assisted-suicide legislation actively exacerbates them by reinforcing the perception that life with a disability or progressive disease is not worth living. This perception not only can lead to preventable deaths by suicide, but it also can create significant or even fatal barriers to accessing health care and needed services. Last year, Maryland passed legislation banning disability discrimination in organ transplants, after some Maryland transplant centers openly stated that they would not serve people with significant developmental or mental health disabilities. But discrimination in other health care contexts continues, as more and more people with disabilities are being denied even basic care for treatable illnesses, including food and water, with medical providers citing their supposedly low quality of life as justification to hasten their deaths. This essentially amounts to opportunistic, involuntary euthanasia of people with disabilities.

As a disability rights advocate, I recognize that our health care system is failing people with disabilities, including disabilities caused by terminal illnesses. The answer, however, is to make sure that people with illness-related disabilities are receiving the supports they need in order to live — not to create a new fast track toward death. People need at-home supports and services in order to stay at their homes while allowing their family members to work and participate in the community — even before they qualify for hospice care. They also need advanced palliative care options, including pain relief and counseling. These supports recognize the value and dignity of all individuals, including those who need help with day-to-day care.

Even those who are expected to die within six months — as the proposed law would require — deserve suicide prevention, not assistance. The disability community is full of people who, with the right care and support, have outlived "six-month" prognoses by decades. Several friends of mine have outlived terminal prognoses by over 30 years. In Oregon, where the law also requires that patients be expected to live less than six months, many patients are still alive six months or more after receiving the lethal prescription.

People with significant disabilities, including people with life-threatening diagnoses, do not need to die to have dignity. Instead, they need access to the things that help them make the most of their remaining time: palliative care, respectful in-home supports, counseling and assistive technology to maximize autonomy. Let's focus on aid in living, not "aid in dying."

Samantha Crane is legal director and director of public policy for the Autistic Self Advocacy Network. Her email is scrane@autisticadvocacy.org.

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