

# **A Disability Rights and Social Justice Perspective Against Assisted Suicide**

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# What's Disability Got To Do With It?

Some question the legitimacy of disability groups "meddling" and trying to "take away" what they see as the general public's right to choose assisted suicide in the face of terminal illness.

# A Little History & Background Before NDY (1983-1996)

Withholding and withdrawing  
life-sustaining treatment

- Bouvia case
- “Give me liberty or give me death”  
cases (Rivlin, McAfee, Bergstedt)

# Terrie's Story

*“At the age of 19, I had an automobile accident. . . . While I was lying in the hospital bed . . . , the doctors would come in and ask my mom if she was ready to pull the plug on me. . . . ‘What kind of life will she have— she won’t. She won’t be able to dance, walk, work, have a social life, or be independent.’ Then they’d work on me. . . . ‘Are you sure this is something you can live with? If I chose no, they would keep me off the ventilator and I would die. I could get injected with Morphine so I couldn’t feel it.”*

*How We Die, Values, Choices, Conflicts*

<http://stories-2.com/HowWeDie/story?sid=4>

# Terrie's Story



# A Little More History & Background

People with disabilities are the people most affected by ending-of-life issues:

Virtually everyone with a terminal illness has a disability, but not everyone with a disability has a terminal illness

# People with serious illnesses and terminal conditions are disabled



PEOPLE WITH  
TERMINAL  
CONDITIONS

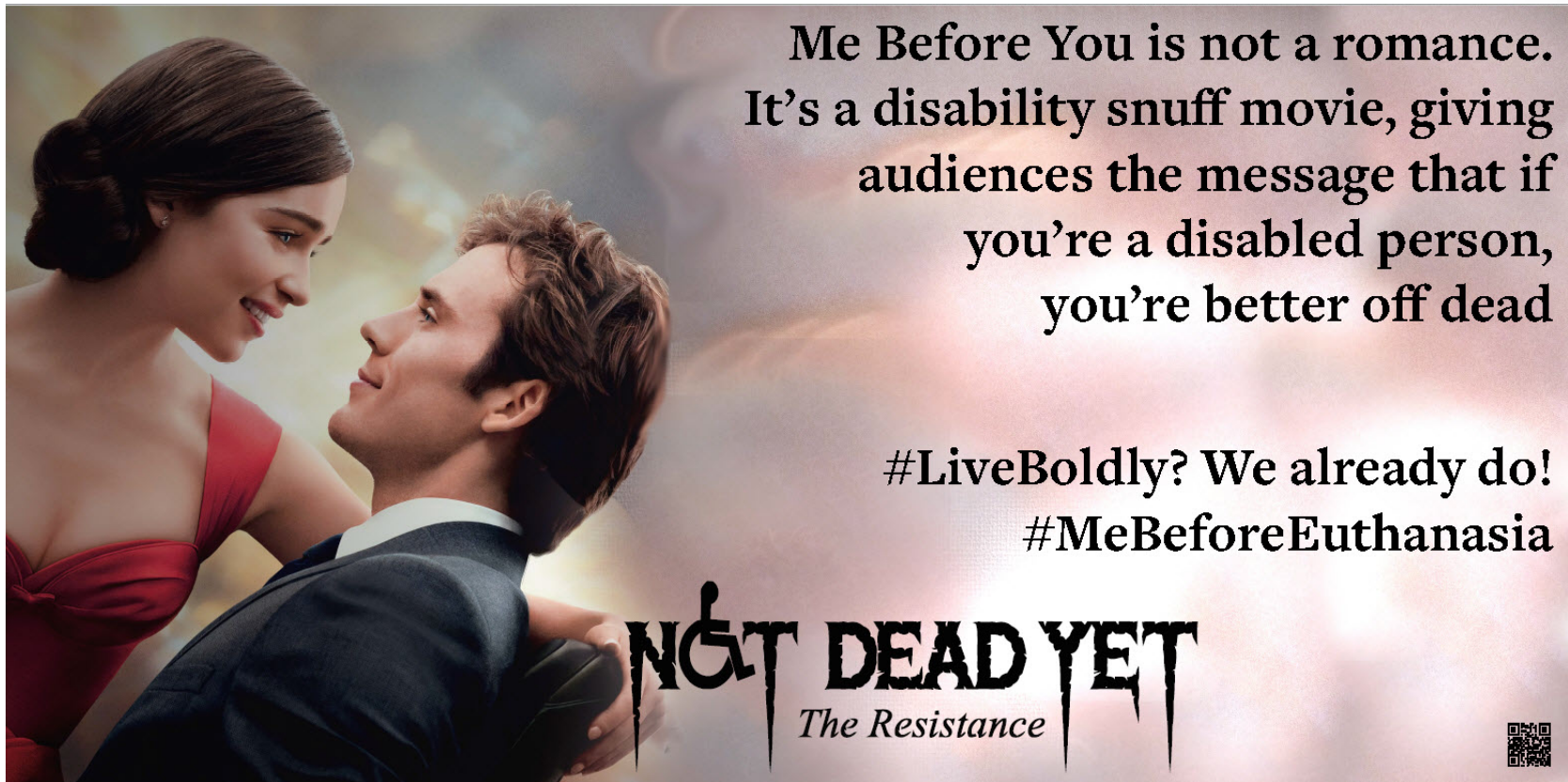
# Reported reasons for assisted suicide: Oregon 1998-2017

<b>End of life concerns</b>	<b>1998-2017</b>
HIS OR HER TERMINAL CONDITION REPRESENTING A STEADY <b>LOSS OF AUTONOMY</b> .	91 %
THE <b>DECREASING ABILITY TO PARTICIPATE</b> IN ACTIVITIES THAT MADE LIFE ENJOYABLE.	90 %
A <b>LOSS OF DIGNITY</b> .	76%
THE LOSS OF CONTROL OF BODILY FUNCTIONS, SUCH AS <b>INCONTINENCE</b> AND VOMITING.	46%
THE PHYSICAL OR EMOTIONAL <b>BURDEN</b> ON FAMILY, FRIENDS OR CAREGIVERS.	44%
INADEQUATE <b>PAIN CONTROL OR CONCERN</b> ABOUT IT.	26 %
THE <b>FINANCIAL COST</b> OF TREATING OR PROLONGING HIS OR HER TERMINAL CONDITION.	4%



# Disability = Death: “Better Dead than Disabled”

- Popular culture romanticizes the death of people like me. From films like “Whose Life Is It Anyway?”, “Million-Dollar Baby,” “The Sea Inside,” and “Me Before You,” people are taught that lives like our are unacceptable.



# Clarifying the Terminology

## Definitions and Euphemisms

- Suicide
- Assisted Suicide
- Death with Dignity
- Aid in Dying
- Medical Assistance In Dying
- Euthanasia (passive, active)

# More History & Background

## 1996 – present

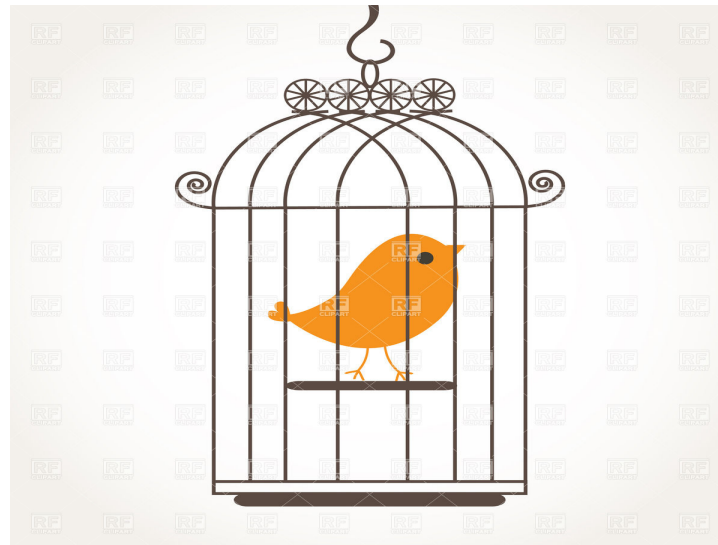
### How U.S. Disability Groups Got Involved

- Two-thirds of Jack Kevorkian's body count in the 1990's was people with non-terminal disabilities. He was our biggest wake up call.
- And the 1996 assisted suicide cases that went up to the U.S. Supreme Court.

# What is the Disability Role? Proverbial Canary in the Coal Mine

The disability experience makes us experts in both:

- The concerns that lead people to request assisted suicide, and
- The dangers of legalizing assisted suicide.



# NDY Strategies & Tactics

## Voicing the Disability Opposition Through:

- Articles, blog
- Conference keynotes and workshops
- Friend-of-the-court Briefs
- Legislative advocacy
- Regulations and policy work
- Non-violent direct action and protest

# Some Individuals with Disabilities

- Some individuals with disabilities support assisted suicide bills
- Autonomy argument (illusion of control) is attractive when you're losing status and control
- People see the problem as the disability, not the discrimination
- Some disabled people accept the “better dead than disabled” view

# Disability Rights Movement

But all of the major disability groups that have taken a position oppose legalizing assisted suicide. They are:

- Run *by* disabled people - “Nothing about us without us”
- Have the research *and* the personal experience
- Make the link with other kinds of discrimination

# Major U.S. Disability Groups Opposed To Assisted Suicide

- ADAPT
- American Assn. of People with Disabilities
- Association of Programs for Rural Independent Living
- Autistic Self Advocacy Network
- Disability Rights Education & Defense Fund
- National Council on Disability
- National Council on Independent Living
- TASH
- The Arc of the United States
- United Spinal Association



# Not A “Slippery Slope,” But An Incremental Strategy

“One safeguard – that physician-assisted death be restricted to the terminally ill – has proven to be especially controversial even among supporters of physician-assisted death. . . . The arguments against the terminal illness requirement illustrate the force of gravity that pulls the policy of physician-assisted death down the slope, and attempts to answer those objections force us to deal with problems of line-drawing on the slope.”

Gunderson, Martin and Mayo, David J., "Restricting Physician-Assisted Death to the Terminally Ill" (PDF) *Hastings Center Report*, November-December 2002. (pp. 17-23)

# Not A “Slippery Slope,” But An Incremental Strategy

“[I]t is reasonable to proceed incrementally and extend physician-assisted death initially only to terminally ill patients. Thus the restriction of physician-assisted death to terminally ill patients should not necessarily be regarded as a permanent restriction.”

Gunderson, Martin and Mayo, David J., "Restricting Physician-Assisted Death to the Terminally Ill" (PDF) *Hastings Center Report*, November-December 2002. (pp. 17-23)

# Euthanasia Elsewhere

## Ever Expanding Eligibility

- “Mature” minors,
- Psychiatric disabilities
- Advance directives / dementia
- Tired of life

# A 50-State Strategy

A big difference between the U.S. and other countries:

Assisted Suicide proponents have worked hard to prevent a case from blowing up in the media.

# Incremental Strategy

- NM bill (90) – death “reasonably foreseeable”
- OR bill (2232) – “produce or substantially contribute to a patient's death”

# Why disability groups oppose AS/E

## Key Arguments

# A. Legalization is unnecessary

1. Suicide as a solitary and autonomous act, is legal and available to anyone.
  - a. There is no “right” to suicide that needs to be accommodated.
  - b. Anyone can kill themselves (e.g. VSED, helium “exit bag”)
  - c. Most people who request AS/E are capable of killing themselves.
2. Everyone has the right to palliative care, even to the point of sedation
3. We don't need to die to have dignity

## B. Assisted suicide is discriminatory

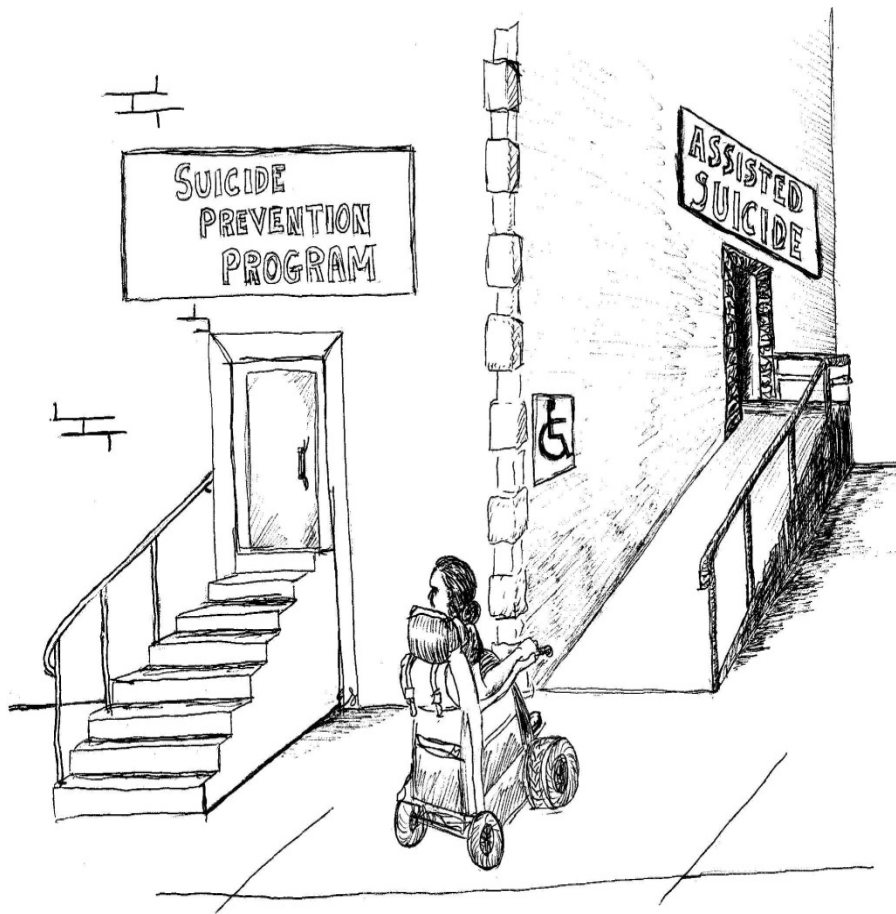
### 1. **Suicide prevention double standard**

a. Non-disabled get suicide prevention, disabled get suicide assistance.

b. Anti-discrimination laws require equal suicide prevention for all.

2. **If you're disabled, the wish to die is seen as "rational"**





Assisted suicide creates a double standard. If you're non-disabled and want to kill yourself, you get suicide prevention. If you have a disability and want to die, you get suicide assistance. It's the ultimate discrimination.

## C. Choice is a slogan, not a reality

**1. There can be no free choice to die while disabled people don't have a free choice in where and how they live**

a. Palliative care

b. Home care v. institutional care

c. Mental health care and peer counseling

d. Poverty, unemployment, disenfranchisement

e. Architectural barriers and lack of transportation

f. These issues impact reported assisted suicide patients' concerns

# C. Choice is a slogan, not a reality

## 2. Profit-driven health-care system / Canaries in the coal mine

- a. Barriers to diagnostic services & treatment
- b. Denial of coverage for treatment / futility policies
- c. Managed care requirements for “recovery,”
- d. Assisted suicide is almost always the cheapest option.
- e. Health care cuts
- f. Health care disparities based on race or other factors, leading to terminal diagnosis and eligibility for assisted suicide

## C. Choice is a slogan, not a reality

**3.** High rates of abuse of elders and disabled people

a. Abuse and neglect in institutions / inhumane conditions

b. Abuse and financial exploitation by family, friends, caregivers

## **D. *Safeguards don't work* – inadequate and not enforced**

1. Prognoses of six months are often wrong
2. Capacity assessment / psychological evaluation
  - a. Not required
  - b. Doesn't screen out treatable mental illnesses or depression
3. Immunity for doctors – “good faith” standard

## ***D. Safeguards don't work – inadequate and not enforced***

4. As Margaret Dore first articulated, no independent witness required at the bedside – If the person struggled, who would know?

5. Minimal reporting by prescribing doctor, no verification, no investigation and no oversight requirements

## ***D. Safeguards don't work – inadequate and not enforced***

6. No sanctions for failing to conform to safeguards, ensure eligibility; no means of enforcement.

7. Disabled lives are treated as “acceptable losses”.

# A good summary

“If assisted suicide is legal, some people’s lives will be ended without their consent, through mistakes, coercion and abuse. No safeguards have ever been enacted, or even proposed, that can prevent this outcome, which can never be undone.”

Marilyn Golden, Disability Rights Education  
& Defense Fund



# Questions