Lives on the Line: Disabled Perspective and the Research Deficit on MAID Presenter: Jacqui Carlson

BACKGROUND

Medical Aid in Dying, MAID, allows terminally ill, mentally competent adults to request a prescribed self-administered medication which hastens death to reduce prolonged suffering. Founded on the priniciples of patient autonomy, dignity, and suffering relief, MAID is eligible for patients diagnosed with terminal illnesses and a prognosis of six or less months to live. The idea of the "good death," an idealized notion of dying surrounding reconciliation of relationship, final goodbyes, autonomy, clear patient-care communication, closure, and minimal suffering. In modern healthcare the idea serves as pallitative care to reduce unneccessary suffering. The concept excludes diverse perspectives and experiences of individuals, disregarding lives of those with disabilities.

DISABLED PERSPECTIVE

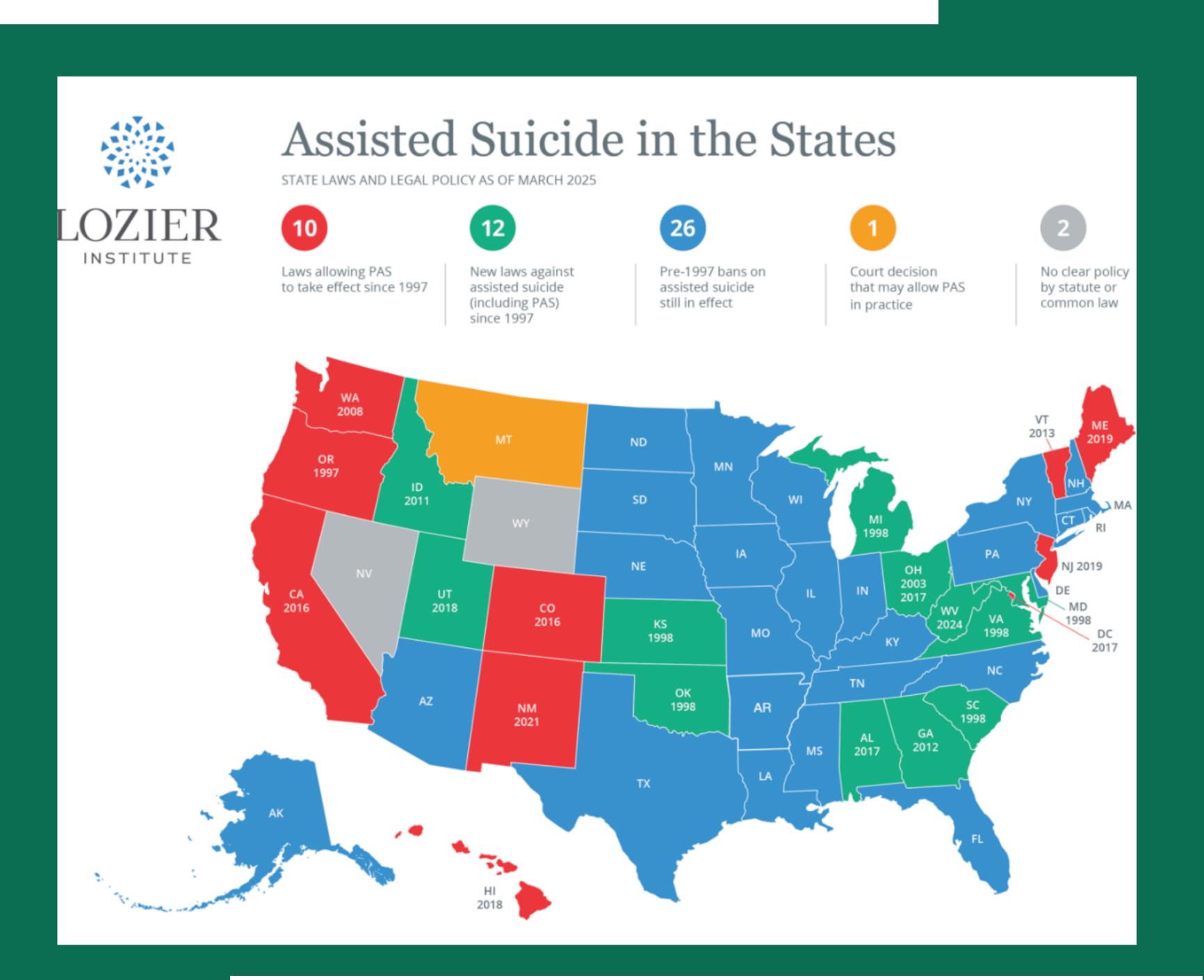
- support for autonomy, emphasis on importance of self-determination
- barriers and stigma causing MAID to be perceived as only viable option
- need for safeguards to be in place, strict criteria and safeguards to protect againist coersion
- systemic ableism, barriers accessing healthcare and social support
- institutation/social pressures exacerbating vulnerabilities reducing likelihood of recieving palliative care/mental health support

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"It's not about people with disabilities; it's about people who have a terminal illness. It's your life, your pain, your treatment, your death - your choice."
Dustin Hankison

"If the day ever comes when my illness is terminal and I face the prospect of a drawn-out painful death, I will want the option of medical aid in dying. I don't know if I will need to use it, but I know I want the assurance that I have the choice." - Michael Martignetti



"personal choice regarding medical treatment should be a fundamental human right" - Dustin Hankinson

COMMON DEBATES FOR MAID

- autonomy and the right to decide,
 empowering individuals to make decisions
 about own end-of-life care
- dignified death, allowing one to die on own terms ("good death")
- provides a compassionate choice and relief for those with prolonged pain

COMMON DEBATES AGAINST MAID

- moral and ethical dilemma
- "slippery slope" broader criteria over time resulting in MAID encompassing non-terminal conditions/illnesses or euthanasia laws expanding
- concern around not all options being exhausted or available (comfort, hospice, and palliative care)
- failure to account for structural inequalities shaping healthcare and support system accessibility

LOOKING FORWARD

Disability moral psychology applied to critique common conception that disability inherently equates to suffering or a lower quality of life. System barriers and inequalities targeting the disabled community fail to be discussed in bioethical debates, leaving gaps in how external factors can influence decision making. Shifting one's perspective requires ethical rethinking and practical reform of healthcare and social services. Forming a more inclusive concept of the "good death," in relation to death with dignity, requires one to note dependency is not interchangeable with indignity. Utilizing disability moral psychology would allow one to critique common conceptions of disabilites equating to suffering or a lower quality of life.