

11 April 2017

MEMO

To: Colorado Board of Health (cdphe.bohrequests@state.co.us)

Fr: Jennifer Ballentine, MA, President, The Iris Project (jennifer@irisproject.net)

RE: **WRITTEN TESTIMONY** regarding hearing on April 19 to finalize “6 CCR 1009-4, Reporting and Collecting Medical Aid-in-Dying Medication Information”

As a longtime leader and advocate for palliative care in Colorado, and the only provider of comprehensive education for healthcare professions on the Colorado End-of-Life Options Act, I appreciate the opportunity to comment on the rules relating to Reporting and Collecting Medical Aid in Dying Medication Information.

I understand that Proposition 106, as now enacted in statute, charges CDPHE with a narrow task: to collect a record when the medical aid in dying (MAiD) drugs are dispensed, “sample” the medical records of physicians prescribing lethal medications, and publish an annual statistical report of the information collected.

Based on what is proposed in the rules, that annual report will be very slim – perhaps only reporting the number of prescriptions filled. This is a dangerous departure from norms established in other states with similar statutes. **Collecting and reporting so little will further obscure and remove this radical practice from the scrutiny it requires, possibly putting patients and physicians at risk. I urge you to expand your brief and follow the model established in other states.**

Such data provide **the only window into revealing any abuse or process problems—or reassuring us that all is well.** Ironically, proponents of the Act relied heavily on data from other states to “prove” there is no such abuse and that the law will “work.” Maybe they are concerned that Colorado data will not support that case as well?

If the same data were collected in Colorado as in other states, **here’s what we could learn:**

Who the patients are – not names but diagnosis, age, gender, ethnicity, or education level; whether insured, receiving hospice care, supported by family or caregivers: **Which terminal conditions are particularly unbearable? Are people choosing the option out of desperation or exploitation – or as a matter of privilege?**

The number and location of doctors doing the prescribing: **Are some doctors turning MAiD into a “specialty” or acting as prescription mills? Are patients in parts of the state not able to find a doctor to prescribe?**

The number of prescriptions filled *and* the number ingested: **In other states, about 30% of patients who receive a MAiD prescription don’t take it. Would that be true in Colorado? Why? And where are the unused drugs?**

The circumstances of the deaths -- at home or in a facility, who was present, which drugs used, how long the death took, whether there were complications: **Are there indications of abuse and/or problems with process? In other states, complications and hospital deaths are on the rise due to cheaper, less reliable drugs being used. Will we see that in Colorado?**

Why patients have chosen the option – loss of control and independence, pain, burden on families: **How is Colorado supporting its seriously ill residents and their families and what improvements in symptom management or emotional/practical support are needed?**

Comparisons with other states and over time on all these points: **Is there anything different about how MAiD is being utilized in Colorado?**

Choosing death by lethal drugs is still unusual in our culture and definitely not a normal medical treatment. Healthcare providers, policy makers, and citizens **need to understand what is motivating MAiD and how to support patients before they take the last-resort step of ending their own lives.** To devise solutions, we must understand the problem. Without data, we know nothing and understand less.