Good Afternoon:

I am writing in opposition to LC0052 because it is impractical and arguably harmful in its specifics. The strategy of ensuring healthcare equity and access is too important and necessary to roll out with flawed logistics.

- I am the father of young men adopted from foster care who live with developmental and physical disabilities. I am an advocate for people with developmental disabilities at the local level here in Benton County and at the state level. My family has been injured by disability bias and hostility. **LC0052** attempts to address important and urgent matters including:
  (i) bias in health care access and accommodations,
  (ii) excessive restrictions on access to ADA-qualified accommodations including support and advocacy for those with developmental disabilities,
  (iii) excessive delays in hospitals adopting best practices for in-person access by support persons and the exclusion of support staff in health care decisions, and
  (iv) confusion between OHA guidelines and hospital policies.
  Those portions of the bill are really important.

- I am a critical care doctor who has worked under conditions of inadequate resources in two epidemics. **LC0052** *requires* medical providers to communicate with various (yet unspecified) case managers, advocacy organizations and governmental agencies *under penalty of civil litigation and loss of licensure*. Finding the support staff's managers and advocates is *not the provider's job*, it is the support staff's job. Taking a critical care doctor away from multiple critically ill patients to do the support staff's job is *counter-productive and unethical*, *delaying and disrupting clinical care* for all other critically ill patients while doing non-clinical work for the support staff. Physicians should not be asked to micromanage the support person's chain of communication, particularly during a crisis. Hospitals should assist those communications; but, the primary role in communications for the support staff chain-of-communication should stay with the support person or their designee.

- I have been an advocate for advance care planning, enhanced care conferences, POLSTs and advance directives for decades. **LC0052** fails to recognize existing, effective platforms that have a record of fairness in difficult decision-making such as evidence-based care conferences, the input of hospital ethics committees when needed, existing teams advocating for unrepresented patients and hospital equity and inclusion councils. **LC0052** instead requires a new, disruptive, uninformed and untested communication pathway.

- I know that other physicians and ancillary staff recognize the same flaw in **LC0052.** Two unsolicited calls today represent a pretty widespread concern: (1) A state thoracic society leader called me today to ask why providers are being required to find the support person's manager, and told me her own story of how difficult it is to find said manager during usual care, let alone crisis care; (2) A family practice colleague called me today with similar concerns, also pointing out correctly that *SECTION 5 actually takes away the autonomy of people with disabilities*.

- **LC0052** correctly defines a support person to include family members. However, as pointed out by colleagues, provisions such LC0052 Section 5 *actually takes away the autonomy of people with disabilities and their qualified family members* who have made good faith advance care planning decisions. It also may violate their HIPAA privacy rights by requiring reporting to agencies not otherwise involved in that person's care. People with disabilities and their families should be allowed the autonomy and privacy of their qualified advance care planning decisions. In this instance and others, LC0052 appears to be written for people with disabilities who are receiving government services to the detriment of people with disabilities who are supported by loving family members. I think this can be corrected by giving the right and responsibility of contacting case managers and government officials to the support person, and not bypassing their role.

- I believe the flaws in **LC0052** can be cured by:
  (i) Giving people supporting those with disabilities a *participatory role* in health care planning and communications, as LC005 does. Legislations should ensure the communications are guided by patient and family wishes.
  (ii) Continue giving the support person or their designee the right and, when appropriate, the obligation to contact their chain of command, including any advocacy and protection personnel they may wish to contact. Until **LC005** gives that communication right and responsibility to the support person rather than the medical provider, it just won't work.
  (iii) Improve discrepancies and delays between hospital restrictions and OHA guidelines applicable to the presence of support staff and other essential individuals. Strive for best-practice models of inclusion.
  (iv) Slow down on new, untested, disruptive and arguably unnecessary communication pathways that pull providers away from critically ill patients while diminishing the responsibility of support people and the autonomy of people living with disabilities.

There is a lot of work to be done for equity and inclusion in healthcare and in justice care. The proponents of LC005 are dedicated to their clients and to healthcare access for our most vulnerable neighbors. I fully support and participate in *our* efforts to increase awareness, access and accommodations for people living with developmental and cognitive disabilities. Let's work together and deliberately to make each day more just and inclusive than yesterday by building highly effective and mutually respectful teams where people can practice at the top of their licensure. **LC005** will not accomplish that goal yet.

Sincerely and respectfully,

John Gotchall, MD
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