



# ACLU Illinois AFFIRMATIVE LEGISLATIVE AGENDA 2024

## **Protect Health Data Privacy Act - HB 4093 & SB 3080 (Rep. A. Williams & Sen. Villanueva)**

Entities in the United States today share most people's personal information without their consent. The Protect Health Data Privacy Act ("PHDPA") will help safeguard the privacy of every Illinoisans' sensitive health information by implementing new privacy protections that will significantly reduce the likelihood that any Illinoisan's health information will end up in the wrong hands.

The PHDPA requires entities that collect health data and/or offer health services ("regulated entities") to offer greater privacy protections to all Illinoisans over their health data. The PHDPA is built on three pillars: (1) transparency, (2) consent, and (3) rights.

The PHDPA will require regulated entities to adopt and publish a Health Data Privacy Policy. HB 4093 makes consent an essential prerequisite to the collection, sharing, sale or storing of any health data. The PHDPA also prohibits regulated entities from selling health data unless provided written consent in a separate agreement specifically authorizing the sale of health data. The PHDPA establishes new privacy rights to empower Illinoisans to protect their health data.

**ACLU Lobbyist:** *Khadine Bennett*

## **Kinship in Demand Act - HB 4781 & SB 3308 (Rep. Evans & Sen. Gillespie)**

Within the framework of the B.H. Consent Decree, the ACLU of Illinois advocates to safeguard foster youth from harm during their time in the care of the Department of Children and Family Services (DCFS) and reduce the length of time they are involved in the DCFS system. To improve outcomes for DCFS-involved youth in relative care and increase the capacity of relatives to become caregivers delivering permanency for more children, this bill removes barriers to equitable financial supports for kinship caregivers by statutorily defining standards for "kinship caregiver home certification" that are no more restrictive than federal law requires and that are in accordance with the recommendations developed by national best practice groups.

The bill increases kinship and guardianship supports and benefits by: requiring that kinship caregivers receive the same level of financial that foster homes receive; helping kinship caregivers with reasonable expenditures needed to ensure that their homes can meet certification standards; providing post-placement supports to kinship guardians similar to supports provided to adoptive families; and requiring DCFS to pursue federal funding opportunities to establish a kinship navigator program.

The bill also provides court oversight for family finding efforts designed to ensure youth have long-term connections with their relatives and amends the Juvenile Court Act to treat adoption and guardianship as comparable alternative ways youth can achieve permanency when reunification is not viable to accommodate the unique family dynamics and needs.

**ACLU Lobbyist:** *Nora Collins-Mandeville*

## Protect Youth Access to Health Care Act - HB 5548 (Rep. Canty)

As attacks on bodily autonomy continue, it is imperative that Illinois law is clear in protecting minors' access to lawful health care - and that parents should not be punished for supporting their child's access to care that is lawful in Illinois. In the 2023 legislative session, more than 100 bills were introduced in dozens of states targeting care that is lawful here in Illinois.

This bill updates our child custody statutes to ensure parents are not at risk of being punished or losing their rights when they help their children obtain needed or lifesaving health care – including when a custody dispute crosses state lines. This bill also expands upon protections for lawful health care already enacted in the Patient and Provider Protection Act.

These changes clarify when Illinois courts have jurisdiction over interstate child custody disputes. For example, an Illinois court could obtain temporary emergency jurisdiction if one parent is supporting lawful health care for a minor in Illinois but their home state outlaws that care. These changes prevent Illinois from being forced to follow laws from other states that are counter to Illinois public policy; they do not expand what is already considered lawful health care protected in Illinois.

**ACLU Lobbyist:** *Aisha Davis & Liza Roberson-Young*

## End of Life Options for Terminally Ill Patients Act - SB 3499 (Sen. Holmes)

**In Partnership:** *Compassion & Choices and Final Options Illinois*

The Illinois End of Life Options for Terminally Ill Patients Act would allow a mentally capable, terminally ill adult with a prognosis of six months or less the option to obtain a prescription medication they may decide to take so they can die peacefully and end their suffering. Qualified individuals must be able to self-administer (i.e., self-ingest) the medication and physicians must inform the requesting individual about all their end-of-life care options, including comfort care, hospice, palliative care, and pain control.

The legislation includes multiple protections to prevent coercion including strict eligibility requirements, two separate physician assessments, and mandatory counseling on all treatment options. No physician, health care provider or pharmacist is required to participate in the law and the individual can withdraw their request for medication or change their mind after receiving the medication and decide not to take it. Medical aid in dying is authorized in 10 states and Washington, D.C. It is a time-tested medical practice that is part of the full spectrum of end-of-life care options, including hospice and palliative care. In the 26 years since the first medical aid-in-dying law went into effect in 1997 in Oregon, there have been no substantiated cases of abuse or coercion. Terminally ill adults deserve access to the full range of end-of-life options in their home state.

**ACLU Lobbyist:** *Khadine Bennett*



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