



May 5, 2025

Senator Anne Carney, Chair
Representative Amy Kuhn, Chair
Joint Standing Committee on Judiciary
State House, Room 438
Augusta, Maine 04333

Re: Testimony in Support of LD 1822, An Act to Enact the Maine Online Data
Privacy Act and Against LDs 1088, 1224, and 1284

Dear Senator Carney, Representative Kuhn, and Members of the Joint Standing
Committee on Judiciary:

My name is Lauren Wille and I am the Legal Director at Disability Rights Maine. DRM is Maine's designated Protection and Advocacy agency, and our mission is to advance justice and equality by enforcing rights and expanding opportunities for people with disabilities in Maine. Thank you for the opportunity to provide testimony in support of LD 1822, and against LDs 1088, 1224, and 1284.

LD 1822 is an important policy that will allow Maine to protect its citizens in the face of rapidly evolving technology. This bill prohibits entities, including for-profit companies, from collecting digital consumer data except where necessary to provide the product or service requested by the consumer. And, crucially, it prohibits such entities from processing consumer data in a way that discriminates or makes unavailable the enjoyment of goods and services on the basis of enumerated statuses, including disability. In contrast to LD 1822, LDs 1088 and 1224 would allow companies to collect personal information as long as the consumer clicks "I agree," or the collection is disclosed in a privacy policy. Very few people read privacy policies, and those of us who do, will be forced to choose between our privacy and accessing a service.

Assistive technology has been tremendously beneficial in helping people with disabilities become more independent, but, as technology expands, so do the privacy concerns. There are apps that help people track chronic pain, transcribe speech for people who are Deaf or hard of hearing, provide wheelchair accessibility information, read aloud written

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information on devices, and provide daily task reminders, to name just a few. These apps are not “health care providers” that are subject to confidentiality under HIPAA. Instead, users might agree to give up privacy protections in order to access the technology. Users may not be aware of the implications of this data being collected, processed, and sold to third-parties. But they may notice that suddenly they are receiving very targeted ads for equipment, certain medications, and other products. The ordinary consumer may not be aware of the exchange of personal data that has occurred to enable this.¹

The recipients of our sensitive data include entities are not subject to confidentiality laws under HIPAA, which only governs health records connected to health care providers. With the proliferation of apps, a great many consumers do not understand that, and how, their personal data is being collected, processed, and sold to other entities. LD 1822 provides protection for all consumers, including consumers with disabilities. In our work at DRM, we see daily how the lack of privacy, through the lens of ableism, leads to rampant discrimination and exploitation of individuals with disabilities. This bill is one step toward safeguarding that usage and allowing people to have control over their personal data and how it is used.

In addition, LD 1822 enables consumers to, among other things, confirm whether their data is being collected, access that data, correct inaccuracies, and opt out of processing and sale of personal data for targeting marketing.

LD 1822 provides comprehensive protections for Mainers, including Mainers with disabilities, and DRM urges this esteemed Committee to vote Ought to Pass. We also urge you to oppose LDs 1088 and 1224, which do not go far enough, and LD 1284, which would repeal our internet privacy law.

Thank you for your time and consideration.

Sincerely,



Lauren Wille, Esq.
Legal Director
Disability Rights Maine

¹ For a comprehensive analysis of the benefits and risks of data collection as it relates to health equity, see Silvia Yee & Mary Lou Breslin, *This Data, Not That Data: Big Data, Privacy, and the Impact on People with Disabilities*, Disability Rights Education and Defense Fund, https://healthlaw.org/wp-content/uploads/2023/03/This-Data-Not-That-Data_Disability-Rights-Education-and-Defense-Fund_FINAL.pdf (last accessed May 5, 2025).