

August 25, 2022

The Honorable Nancy Pelosi
Speaker of the House
U.S. House of Representatives
H-232, the Capitol
Washington, DC 20515

Dear Speaker Pelosi:

Effective privacy legislation must address and protect data that is particularly sensitive for disabled people, including people with mental health disabilities and chronic illnesses. We, the undersigned disability rights and disability justice organizations, are heartened to see that H.R. 8152, the American Data Privacy and Protection Act (ADPPA) includes many provisions that will help protect people with disabilities. We ask that you retain and improve these provisions as the bill moves forward.

Disabled people are at particular risk from the misuse of data, including unscrupulous, exploitative, risky, or even dangerous uses of data. For example, recent news stories have covered researchers and tech companies' efforts to create algorithms that can predict diagnoses of depression, anxiety, or autism using the content of users' social media posts or biometric data from cell phone sensors.¹ And many types of information and services, including location data, browser history, search history, and health data (collected by apps, wearables, or other technology) may reveal information that could identify people with disabilities, be used to infer a person's disability status, or identify past or predicted future experiences of disabilities.

That data, which may not be accurate, can be used to discriminate against people with disabilities, who already face significant discrimination and prejudice in every aspect of society, including in employment, housing, education, health care, and the criminal legal system. Use and misuse of data affecting disabled people can lead to shaming and stigma, or exacerbate existing inequalities and perpetuate patterns of discrimination. For example, landlords and property management companies can use data correlated with disability (like higher rates of evictions, arrests, and domestic violence) to deny housing,² or law enforcement can use data indicating mental illness to profile community members as potentially dangerous.³

We commend the House of Representatives on its progress on the ADPPA, which provides important protections for disabled people beyond those available in other applicable disability rights laws. Those protections include defining health and disability data as sensitive and thus given extra protection,

¹ See e.g., Rolfe Winkler, *Apple is Working on iPhone Features to Help Detect Depression, Cognitive Decline*, Wall Street J. (Sept. 21, 2021), <https://www.wsj.com/articles/apple-wants-iphones-to-help-detect-depression-cognitive-decline-sources-say-11632216601>; Northwestern U., *Using AI to Identify Mental Health Issues on Social Media* (Feb. 24, 2021), <https://www.mccormick.northwestern.edu/artificial-intelligence/inside-our-program/stories/2021/using-ai-to-identify-mental-health-issues-on-social-media.html>.

² Kaveh Waddell, *How Tenant Screening Reports Make It Hard for People to Bounce Back From Tough Times*, Consumer Reports (Mar. 11, 2021), <https://www.consumerreports.org/algorithmic-bias/tenant-screening-reports-make-it-hard-to-bounce-back-from-tough-times-a2331058426/>; Jerusalem Demsas, *Why People are Getting Evicted for Calling 911*, Vox (Mar. 15, 2021), <https://www.vox.com/22307509/crime-free-evictions-for-calling-911>.

³ Mason Marks, *Artificial Intelligence-Based Suicide Prediction*, 21 Yale J.L. & Tech. 98 (2019), https://yjolt.org/sites/default/files/21_yale_j.l._tech._special_issue_98.pdf.

defining disability as a protected class, and requiring that covered entities make their policies and consent mechanisms accessible to people with disabilities. We hope that the House retains and improves these protections as the bill moves through the legislative process.

Sincerely,

The Center for Independent Living - Berkeley, California
Access Ready
American Association of People with Disabilities
The Arc of the U.S.
Autistic People of Color Fund
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
California Foundation for Independent Living Centers
The Coelho Center for Disability Law, Policy and Innovation
Democratic Disability Caucus of Florida
Democratic Disability Caucus of Palm Beach County
Disability Law and Policy Program of Syracuse University College of Law
Disability Rights Bar Association
Disability Rights Education & Defense Fund
Florida Voices for Health
Hearing Loss Legal Fund
Justice in Aging
Little People of America
National Association of Councils on Developmental Disabilities
National Association of the Deaf
National Association for Rights Protection and Advocacy
National Disability Rights Network
National Organization of Nurses with Disabilities
Not Dead Yet
RespectAbility
United States International Council on Disabilities