



Testimony from the National Health Law Program
SENATE FINANCE COMMITTEE HEARING ON
ARTIFICIAL INTELLIGENCE AND HEALTH CARE:
PROMISE AND PITFALLS

February 8, 2024

The National Health Law Program (“NHeLP”) submits this testimony to the Senate Finance Committee regarding the use of algorithms and artificial intelligence (AI) systems in health care. NHeLP is a public interest law firm that fights for equitable access to quality health care for people with low incomes and underserved populations, and for health equity for all. For over fifty years, we have litigated to enforce health care and civil rights laws, advocated for better federal and state health laws and policies, and trained, supported, and partnered with health and civil rights advocates across the country. NHeLP’s testimony is based on our long history of advocacy to protect Medicaid beneficiaries against harmful automated decision making systems (ADS), such as algorithms and AI.

For decades NHeLP has identified errors, discrimination, and due process violations in ADS and fought against them. We have real-world experience fighting the harm caused by technology in public benefits, knowledge about the how and why such harms occur, and practical ideas about policies necessary to protect against such harms.¹ This experience gives us a different and needed perspective on policy efforts to protect against harmful AI. We understand what the systems look like on the ground and how they impact people’s rights. As part of our work to ensure technology helps rather than harms Medicaid enrollees, NHeLP has partnered with other advocates, including tech justice advocates, to advance protections in public benefits programs so that people are not wrongfully denied benefits they need. For example, we have partnered with [Upturn](#) and [Legal Aid of Arkansas](#) to form the [Benefits Tech Advocacy Hub](#) to give advocates tools to fight harmful benefits technology and force greater transparency so that harm to individuals can be identified, prevented, or reduced earlier in the technology’s lifecycle. In addition to ongoing advocacy regarding individual ADS, NHeLP has also released our

¹ See Nat’l Health Law Program, [Fairness in Automated Decision Making Systems, https://healthlaw.org/algorithms/](https://healthlaw.org/algorithms/).

[Principles for Fairer, More Responsive Automated Decision-Making Systems](#) (“ADS Principles”), which reflect our years of work regarding ADS, including AI, and what features and protections are needed in responsible ADS.

In the past several years as interest in algorithmic accountability has grown, we consistently see proposals to mitigate the harms of ADS that fail to recognize the impact on public benefits, for which it is well-recognized that people have a “brutal need.”² Protections of notice, transparency, and explainability already exist, are constitutionally required, and must be fully recognized and enforced in any AI policies that impact public benefits.³ We welcome the opportunity to offer testimony to this committee. NHeLP asks that this Committee:

- Use a broad definition of AI to include all of the types of AI currently causing harm to people’s access to care.
- Embrace NHeLP’s ADS Principles regarding transparency, protection of civil rights, user-focus, validity, mitigation of bias, and humility and redundancy as well as the work of the Benefits Tech Advocacy Hub in the Committee’s work on algorithms and AI systems in health care.
- Recognize that individuals receiving health care provided through a public benefit program such as Medicaid have specific rights and protections that demand greater transparency, nondiscrimination, and accountability than many AI fairness proposals include; these rights cannot be ignored in legislative approaches. We also ask that business interests such as trade secret protections not be allowed to stand in the way of transparency about the source, testing, and decision-making of AI.

AI Protections Must Include a Broad Definition of AI to Address Current ADS Harms

Automation can facilitate access to benefits and increase efficiency, but ADS that is poorly designed, based on biased research or data sets, not implemented with appropriate testing, and not adequately monitored creates significant harm. Particularly

² *Goldberg v. Kelly*, 397 U.S. 254 (1970).

³ *Id.*; see also Jane Perkins, Nat’l Health Law Program, *Demanding Ascertainable Standards*, Nat’l Health Law Program (June 11, 2021), <https://healthlaw.org/resource/demanding-ascertainable-standards-medicaid-as-a-case-study/>.

in Medicaid, this harm affects people who have very few resources to absorb it.⁴ When ADS harms Medicaid recipients, they have life altering losses of benefits; this loss of Medicaid coverage is a well-recognized harm.⁵ However, not all ADS creating harms in Medicaid meet all definitions of AI. For example, when asked to inventory AI use cases in response to Executive Order 13960 regarding the use of trustworthy AI in the federal government, the Department of Health and Human Services created a three-page list.⁶ This list does not include the Federal Marketplace for health care coverage that processed applications and plan selection for over 20 million people, with more being transferred to Medicaid, through an automated system that implements a complex system of eligibility rules, including state specific rules, to determine whether a person is eligible for health coverage or not.⁷ While the Federal Marketplace, like many ADS in

⁴ See, e.g., Sarah Grusin et al., Nat'l Health Law Program, FTC Complaint: Request for Investigation into Deloitte's Texas Medicaid Eligibility System 30-37 (Jan. 31, 2024), <https://healthlaw.org/resource/ftc-complaint-request-for-investigation-into-deloittes-texas-medicaid-eligibility-system/>.

⁵ See, e.g., *Smith v. Benson*, 703 F. Supp. 2d 1262 (S.D. Fla. 2010); Benjamin D. Sommers et al., *Health Insurance Coverage and Health—What the Recent Evidence Tells Us*, 377 NEW ENGLAND J. MEDIC. 586 (2017), <http://www.nejm.org/doi/full/10.1056/NEJMs1706645>; Benjamin D. Sommers, *State Medicaid Expansions and Mortality, Revisited: A Cost-Benefit Analysis*, 3 AM. J. OF HEALTH ECON. 392 (2017), <https://dash.harvard.edu/bitstream/handle/1/27305958/Mcaid%20Mortality%20Revisited%20DASH%20Version.pdf?sequence=1&isAllowed=y>; Allyson G. Hall et al., *Lapses in Medicaid Coverage: Impact on Cost and Utilization Among Individuals with Diabetes Enrolled in Medicaid*, 48 MEDIC. CARE 1219 (2008); Andrew Bindman et al., *Interruptions in Medicaid Coverage and Risk for Hospitalization for Ambulatory Care-Sensitive Conditions*, 149 ANNALS INTERNAL MED. (2008), <https://www.commonwealthfund.org/publications/journal-article/2008/dec/interruptions-medicaid-coverage-and-risk-hospitalization>; Steffie Woolhandler & David U. Himmelstein, *The Relationship of Health Insurance and Mortality: Is Lack of Insurance Deadly?*, 167 ANN. INTERN. MED. 424 (2017), <http://annals.org/aim/fullarticle/2635326/relationship-health-insurance-mortality-lack-insurance-deadly>; Aviva Aron-Dine, Ctr. on Budget and Policy. Priorities, *Eligibility Restrictions in Recent Medicaid Waivers Would Cause Many Thousands of People to Become Uninsured* (Aug. 9 2018), <https://www.cbpp.org/sites/default/files/atoms/files/8-9-18health.pdf>.

⁶ U.S. Dep't of Health & Human Servs., Department of Health and Human Services: Artificial Intelligence Use Cases Inventory, <https://www.hhs.gov/about/agencies/asa/ocio/ai/use-cases/index.html>.

⁷ Ctrs. for Medicare & Medicaid Servs., *Under the Biden-Harris Administration, Over 20 Million Selected Affordable Health Coverage in ACA Marketplace Since Start of Open Enrollment Period, a Record High* (Jan. 10, 2024),

Medicaid that have caused harm, is not a complex machine learning version of AI, it is the type of AI that can and has caused immense harm to people who are wrongly determined ineligible for coverage or assistance paying their premiums. Nor did HHS's list include the millions upon millions of federal dollars that have been spent building state automated eligibility systems, many of which have or have had significant issues, causing improper terminations of Medicaid coverage and harm millions of individuals.⁸ These Medicaid eligibility systems annually process the nearly 90 million people enrolled in Medicaid and CHIP throughout the country.⁹

Both the NHeLP and Benefits Tech Advocacy Hub websites include examples of harm from various types of AI in Medicaid. Wrongful decisions by AI in Medicaid have caused people to lose health care coverage for which they were eligible and not be able to fix the problem without advocacy intervention, lose eligibility for and need hours of critical home and community-based services (HCBS) that keeps people safe and healthy in their homes and out of institutions. They have also denied needed care through harmful prior authorization tools based in fiscal decisions rather than generally accepted standards of care.¹⁰ Regardless of the level of sophistication or complexity of the AI, protections must be in place. The harm from machine learning is no greater than that generated by an algorithm written by a State Medicaid agency or its contractor to determine eligibility for HCBS—both deny critical care and cause life-long harm. We ask that this Committee not be distracted by the complexity of AI such as machine learning, but recognize that any legislative action regarding AI should be broadly inclusive in order to protect against harm.

Embrace NHeLP's Expertise and that of its Partners

NHeLP's long history of advocacy on ADS issues has led us to think about preventive advocacy rather than only addressing ADS after they have begun to harm individuals. Our ADS Principles and work with the Benefits Tech Advocacy Hub recognize that there are benefits to automation, but those must be realized while minimizing the drawbacks. There must be thoughtful policy interventions that address each step of the ADS lifecycle so that harm can be recognized, evaluated, and remediated. Our recent

<https://www.cms.gov/newsroom/press-releases/under-biden-harris-administration-over-20-million-selected-affordable-health-coverage-aca>.

⁸ See, e.g., TX FTC Complaint *supra* note 4, at 12-21.

⁹ Medicaid.gov, October 2023 Medicaid & CHIP Enrollment Data Highlights, <https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>.

¹⁰ See *generally* Benefits Tech Advocacy Hub, Case Studies Library, <https://www.btah.org/case-studies.html>.



experiences, including those related to the unwinding of the Medicaid continuous coverage provisions during the public health emergency, reiterate to us that ADS are often generating harmful, yet preventable, errors.¹¹ Importantly, our work understands that ADS, even if carefully created and monitored, is likely going to have errors either because of the system or because of user interaction with the system. Therefore, we have thought through both the protections needed for the system itself and the processes around the system that should function as a safety net to prevent harm.

A key part of NHeLP's work is our relationships with advocates across the country.¹² These relationships are critical to our ADS work because they help identify systems that are proposed or are actively generating harm. Our work and that of our partners, including our tech justice partners, means we have real-world examples of problems, their impact on individuals, and solutions for preventing those harms. Our community and partners have the right mix of knowledge, including legal and technical, to identify problems and solutions that will actually work.

Preventing Harm from AI in Health Care Must Incorporate Existing Legal Rights

New AI fairness and accountability principles have been emerging over the past several years, but not all of them recognize existing legal rights in recommendations of transparency and protections against bias. And few tackle the significant barrier to transparency of trade secret and similar protections. While we recognize the business interests in technology, key legal rights of those impacted by the technology must be acknowledged in AI policy efforts. Importantly, some level of transparency is required when ADS is making decisions about public benefits due to constitutional due process requirements.¹³ This is not "optional" or a "best practice." In addition, public benefits ADS transparency may also be required by other laws, including public records.¹⁴

¹¹ See, e.g., Nat'l Health Law Program, Fairness in Automated Decision Making, <https://healthlaw.org/algorithms/>; TX FTC complaint, *supra* note 4.

¹² See, e.g., Nat'l Health Law Program, Health Law Partnerships, <https://healthlaw.org/health-law-partnerships/>.

¹³ Perkins, *supra* note 3.

¹⁴ See, e.g., *K.W. by D.W. v. Armstrong*, No. 1:12-CV-00022-BLW-CWD, 2023 WL 5431801 (D. Idaho Aug. 23, 2023) (ordering disclosure of manual information related to algorithm for services was necessary to comply with due process and did not infringe upon copyright restrictions); *Salazar v. D.C.*, 750 F. Supp. 2d 65 (D.D.C. 2010) (providing limited protected order to disclosed standards that were asserted to be protected by business interests); *Arkansas Dep't of Com., Div. of Workforce Servs. V. Legal Aid of Arkansas*, 2022 Ar. 130, 546 S.W.3d 9 (2022) (finding trade secret protections in public records did not limit beneficiary access to algorithm used in unemployment algorithm).

As described in NHeLP's ADS Principles regarding transparency, without transparency throughout the lifecycle of an ADS, problems and the harms they cause will likely come to light only when sufficient numbers of people are harmed to identify there is a problem. But even then, if transparency is not required, that the ADS is at fault and what needs to be addressed cannot occur and harm is likely to continue. For many impacted by ADS in Medicaid, once the harm has occurred, it is not easily ameliorated either because they do not readily return to the program, they have difficulty re-enrolling, or the service denial causes a domino effect of harms.¹⁵

Conclusion

We ask that this committee recognize that efforts to address harm from ADS in health care must include approaches to address those harms in Medicaid and other government-funded health care programs. And that those efforts recognize not only the unique rights of enrollees, but the extent of harm as well. Our ADS Principles set forth our asks regarding algorithmic fairness and we welcome questions and conversations to further provide information and guidance on policy solutions that will provide meaningful protections to current harms.

For further information or questions about this testimony, please contact Elizabeth Edwards at the National Health Law Program by email at edwards@healthlaw.org.

¹⁵ Sarah Sugar et al., ASPE Office of Health Policy, *Medicaid Churning and Continuity of Care: Evidence and Policy Considerations Before and After the COVID-19 Pandemic* (Apr. 12, 2021),

https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//199881/medicaid-churning-ib.pdf (finding that Medicaid churn leads to periods of uninsurance, delayed care, and less preventative care for beneficiaries and higher administrative costs, less predictable state expenditures, and higher monthly care costs); Sophie Novack, *As Texas Throws 1.8 Million Off Medicaid, Children Pay the Price*, TEXAS MONTHLY (Jan. 25, 2024), <https://www.texasmonthly.com/news-politics/medicaid-disenrollment-texas-children/> (describing the impact of eligibility system requesting documentation it should already have access to and a child losing services and enrollment in treatment program critical to her walking and balance); Sarah Grusin & Elizabeth Edwards, Nat'l Health Law Program, *Recent Filing in Lawsuit Describes Medicaid Unwinding Harms in Tennessee* (Aug. 2, 2023) (describing issues with TennCare's eligibility system, including having to repeatedly submit the same information, not properly being found eligible, and requiring advocacy intervention); see generally Nat'l Health Law Program, *A.M.C. v. Smith*, Middle District of Tennessee, <https://healthlaw.org/resource/a-m-c-v-smith-middle-district-of-tennessee/> (case involving issues with notices, the eligibility system, disability discrimination, and access to fair hearings to address errors).