J.R., Appellant, v. **HORIZON NJ HEALTH,** Respondent.	SUPERIOR COURT OF NEW JERSEY, APPELLATE DIVISION DOCKET NO.: A-002028-21 CIVIL ACTION On Appeal from a Final Decision of the Division of Medical Assistance and Health Services OAL DOCKET NO.: HMA-4114-2021 Sat Below: Hon. Ernest Bongiovanni, A.L.J.

BRIEF OF *AMICUS CURIAE* NATIONAL HEALTH LAW PROGRAM.

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INTEREST OF AMICUS CURIAE

The National Health Law Program (NHeLP), founded in 1969, protects and advances health rights of low-income and underserved individuals and families. NHeLP advocates, educates, and litigates at the federal and state levels to advance health and civil rights in the United States. NHeLP works in depth with federal and state Medicaid laws, including those addressing notice and hearing rights and, as such, has interest in this case.

SUMMARY OF ARGUMENT

Health care decisions are increasingly made by automated decision-making systems (ADS). Science is increasingly identifying problems with ADS in health care and calling for accountability, including transparency. This cases raises important questions about the due process rights of Medicaid beneficiaries when decisions are made about their coverage using ADS that are not transparent to them.

ARGUMENT

Innovations in health care have led state Medicaid agencies to rely increasingly on automated decision-making systems (ADS). Sometimes referred to as "artificial intelligence," ADS make eligibility and service coverage decisions using algorithms based on activities such as historical utilization patterns, claims data, and health care provider practices. ADS include assessment tools and care guidelines that use data from individuals to either make or provide substantial guidance in making decisions to approve or deny Medicaid coverage. Although

often adopted under the guise of furthering objectivity, ADS have shown to have a range of problems including failing to properly account for outliers and bad coding. ADS have also created limits on services that are not consistent with the underlying policies they are intended to implement. As ADS undergo increasing scrutiny, they have been shown to wrongfully deny care to certain population groups or otherwise fail to accurately capture the needs of all populations to which they are applied.

As a result, many approaches regarding fairness and accountability in the use of health care ADS focus on transparency to facilitate the identification of errors and biases. As discussed below, these approaches reflect a long-standing, well-established constitutional and statutory framework for ensuring that Medicaid beneficiaries receive adequate due process before their coverage is denied, reduced, or terminated.

Coverage decisions made through use of ADS are not exempted from these vital beneficiary protections. The rationale is clear: Without sufficient information to understand the standards used to approve, reduce, or deny coverage, Medicaid beneficiaries, like J.R., are left without the information necessary to understand or challenge adverse decisions. Failure to provide sufficient information about the basis of a Medicaid decision means that beneficiaries cannot identify when decisions may have missed aspects of their condition, used the wrong standard, or otherwise missed elements of medical necessity for the services they need.

I. Transparency Helps Address Bias and Errors in Health Care Automated Decision-Making.

A. Secrecy in Health Care Automated Decision-Making Systems Often Hides Inequities and Errors.

Health care ADS are increasingly being questioned and investigated for bias and errors. Even long-standing, well-used health care guidelines are being questioned and proven to include bias, assumptions based on long dispelled medical myths, and errors due to narrow data sets. *See, e.g.,* Donna M. Christensen et al., *Medical Algorithms Are Failing Communities of Color*, Health Affs. (Sept. 9, 2021) (summarizing articles identifying issues in medical algorithms); Ziad Obermeyer et al., *Dissecting Racial Bias in an Algorithm Used to Manage the Health of Populations*, Science (Oct. 25, 2019) (finding a widely used algorithm denied care to Black patients with the same level of need as equally sick White patients). For example, numerous purported racial and ethnic genetic predisposing differences regarding muscle mass, pain sensitivity, lung function, and other biomarkers have been debunked; nevertheless, these differences have been included in health care ADS for decades. U.S. Dep't Health & Human Servs., Agency for Healthcare Rsch. & Quality, *Impact of Healthcare Algorithms on Racial and Ethnic Disparities in Health and Healthcare: Systemic Review Protocol* 1-2 (Jan. 25, 2022). Moreover, bias in health care ADS is not limited to race. During the first year of the COVID-19 pandemic, the federal Office of Civil Rights identified medical rationing ADS tools that were biased against people with

disabilities. U.S. Dep't Health & Human Servs., HHS Office for Civil Rights, Bulletin: Civil Rights, HIPAA, and COVID-19 (Mar. 28, 2020) (noting use of quality of life standards that reflected outdated assumptions and norms).

Importantly, removing or recalibrating race and other factors that may be associated with bias does not automatically fix health care ADS. *See, e.g.,* Yoonyoung Park et al., *Comparison of Methods to Reduce Bias from Clinical Prediction Models of Postpartum Depression,* JAMA Network Open (Apr. 15, 2021) (discussing how using broader, more diverse data was the best method to improve the decision model's accuracy); *see also* Chuan Hong et al., *Predictive Accuracy of Stroke Risk Prediction Models Across Black and White Race, Sex, and Age Groups,* JAMA (Jan. 24/31, 2023) (finding improved modeling techniques and expanded data sets were needed to improve model performance, including for models used for decades to predict stroke risk). The original sources of data can also influence the effectiveness of health care ADS, leading to the denial of care. *See, e.g.,* Jessica K. Paulus & David M. Kent, *Predictably Unequal: Understanding and Addressing Concerns that Algorithmic Clinical Prediction May Increase Health Disparities,* Nature 4-5 (July 30, 2020).

In addition to issues regarding the underlying science, state Medicaid agencies have used ADS that failed to account for medical conditions and care needs that should have been included based on the policies that the ADS was supposed to implement. *See, e.g.,* Colin Lecher, *What Happens When an Algorithm*

Cuts Your Health Care, The Verge (Mar. 21, 2018). For example, Arkansas relied on an ADS based in a validated assessment tool to determine home care hours. Despite assertions by the creator of the tool that "It's not simple…you're going to have to trust me that a bunch of smart people determined this is the smart way to do it," errors were discovered. *Id.* This occurred when the creator of the assessment tool was asked in court to hand code an individual's assessment as it was applied in Arkansas. *Id.* Medicaid advocates in other states have identified similar problems with health care ADS, and the underlying assessment tools not properly reflecting policies. *See* Benefits Tech Advocacy Hub, Case Study Library, https://www.btah.org/case-studies.html (listing Arkansas, Missouri, Idaho, and Wisconsin cases studies of ADS issues in Medicaid home and community-based services).[1]

Although ADS are used as "medical necessity" determinations, they do not always follow the program guidelines and may otherwise deny care inappropriately. In Medicare, challenges to coverage determinations by ADS are an ongoing issue because older adults and certain people with disabilities not receiving care that should be covered based on stated Medicare policies. *See* Carey Ross & Bob Herman, *Denied by AI: How Medicare Advantage Plans Use*

[1] Counsel have included the cited webpages in the appendix and can supplement that appendix with all other documents cited other than statutes, regulations, and reported cases if the court so prefers.

Algorithms to Cut Off Care for Seniors in Need, STAT (Mar. 13, 2023). Based on decisions deemed "at best, speculative" by a federal judge ruling in a Medicare case, ADS predicting need are often hidden behind claims of "That's proprietary," and determinations that patients can be managed at a lower level of care, even though the results are in contrast to what the providers are seeing in the patient in front of them. *Id.* Similarly, in Wisconsin, ADS used to determine Medicaid home and community-based services eligibility failed to find people with development disabilities not connected to intellectual disabilities eligible for the program, even though the program eligibility criteria clearly included such disabilities. Benefits Tech Advocacy Hub, Wisconsin Case Study *supra.* Discrepancies between underlying policy and the ADS are difficult to identify if there is little transparency about the basis of the decision.

B. Transparency Is a Well-Acknowledged Necessity for Health Care ADS Fairness.

Increasing acknowledgement of problems with the use of health care ADS has led to efforts to address bias and other issues. At the heart of most of these efforts is ensuring that needed information about the ADS is transparent to individuals who are subjected to them, including, where relevant, underlying data sets, training data, statistical analyses, logic trees, assumptions, and code. *See, e.g.,* Melissa D. McCradden, *Ethical Limitations of Algorithmic Fairness Solutions in Health Care Machine Learning,* The Lancet: Digital Health (May

2020); Paulus & Kent, *supra*; Trevor Locke et al., *Preventing Bias and Inequities in AI-Enabled Health Tools* 11-14 (July 6, 2022); Natalia Norori et al., *Addressing Bias in Big Data and AI for Health Care: A Call for Open Science,* Patterns (Oct. 8, 2021). Transparency has been key in identifying problems with existing health care ADS. *See* Section I.1, *supra* at 3-5 (discussing Obermeyer and Arkansas home care studies); Benefits Tech Advocacy Hub, Missouri Case Study, *supra* (describing how testing of an algorithm for Medicaid services that was available for public comment found significant errors and biases in eligibility). Indeed, transparency is key in most of the federal efforts to address ADS fairness, including in health care. *See* U.S. Dep't Commerce, Nat'l Inst. Stds. & Tech., *Towards a Standards for Identifying and Managing Bias in Artificial Intelligence* (Mar. 2022); U.S. Dep't Health & Human Servs., *Trustworthy AI (TAI) Playbook* (Sept. 2021); Exec. Order No. 13960, 85 Fed. Reg. 78939 (Dec. 8, 2020).

ADS accountability model discussions of transparency commonly the idea of notice to individuals that automated guidelines or assessment tools have been used, along with some explanation of how they contributed to the basis of the decision or results. *See, e.g.,* McCradden, *supra* (finding documentation and rationale is critical for fair medical decision making as is communication with patients about the rationale); *Trustworthy AI Playbook* at 19 (recommending the ADS outputs are sufficiently clear and comprehensible to end users such that they can take appropriate action); White House Office of Sci. & Tech. Policy, *Blueprint*

for an AI Bill of Rights: Making Automated Systems Work for the American People 6, 40-45 (Oct. 2022) (describing notice and explanation as a guiding principle).

II. Due Process Rights for Medicaid Beneficiaries Are Clear and Known.

Importantly for Medicaid beneficiaries, many of the accountability and transparency concepts about how an ADS tool is used and the basis of its decision are already required by due process. It is well established that Medicaid beneficiaries have a property interest, or entitlement, to their benefits that is protected by the Due Process Clause of the Fourteenth Amendment. Over 50 years ago, *Goldberg v. Kelly*, 397 U.S. 254 (1970), recognized that termination of Medicaid benefits "pending resolution of a controversy over eligibility may deprive an eligible recipient of the very means by which to live while he waits." *Id.* at 264. Thus, "due process" requires "that a recipient have timely and adequate notice detailing the reasons for a proposed termination, and . . . [t]he opportunity to be heard . . . tailored to the capacities and circumstances of those who are to be heard." *Id.* at 267-69.

Similarly, the Medicaid Act and its implementing regulations require the state Medicaid agency and entities with which it contracts, including managed care organizations, to provide each Medicaid recipient with adequate written notice and an opportunity to be heard before services are denied, reduced, or terminated. 42 U.S.C. §§ 1396a(a)(3), 1396u-2(a); 42 C.F.R. §§ 431.210, 438.404. The Medicaid

regulations expressly incorporate the due process safeguards outlined in *Goldberg*. *See* 42 C.F.R. § 431.205(d); *see also* N.J.A.C. § 10:49-10.4(a)(2) (echoing the due process requirements found in *Goldberg* and mandating DMAHS to provide "adequate notice detailing the reasons for the proposed action").

The written notice required by due process must provide the recipient with individualized information they can use to decide whether the agency has made mistakes in reducing their benefits. *Goldberg*, 397 U.S. at 267-68 (finding due process requires a notice "detailing the reasons for a proposed termination" and including "the legal and factual bases" for the decision); *Elder v. Gillespie*, 54 F.4th 1055, 1064 (8th Cir. 2022) (finding notice concerning decision made using an ADS was not sufficiently particularized where it was not as "specific as reasonably practicable about the beneficiary's health conditions and reduced benefits") (citation omitted); *Bliek v. Palmer*, 102 F.3d 1472, 1476 (8th Cir. 1997) (stating that a "plainly written, informative notice" is imperative for public benefits); *Ortiz v. Eichler*, 794 F.2d 889, 893 n.4 (3d Cir. 1986) (noting that "the need for specific and detailed notice of the bases for adverse agency action in order to guard against the erroneous deprivation of these benefits," is "well recognized"); *Vargas v. Trainor*, 508 F.2d 485, 489 (7th Cir. 1974) (collecting cases regarding the "categorical . . . requirement" that a notice include the reasons or grounds for the action).

A proper due process notice also informs the individual whose coverage is being reduced or terminated of their right to an impartial pre-termination hearing and how to exercise that right. *Goldberg*, 397 U.S. at 267-68. "Adequate notice is integral to the due process right to a fair hearing, for the 'right to be heard has little reality or worth unless one is informed.'" *Bliek*, 102 F.3d at 1475 (quoting *Mullane v. Cent. Hanover Bank & Tr. Co.*, 399 U.S. 306, 314 (1950)). The written notice apprises a beneficiary of their right to hearing and "permit[s] adequate preparation for . . . an impending hearing." *Memphis Light, Gas & Water Div. v Craft*, 436 U.S. 1, 14 (1978); *K.W. ex rel. D.W. v. Armstrong*, 789 F.3d 962, 973 (9th Cir. 2015) (noting in a case involving ADS that "[a] primary purpose of providing adequate notice to participants is to enable them to prepare a defense for a hearing"). Thus, "in the absence of effective notice, the other due process rights afforded [to] a [beneficiary] . . . are rendered fundamentally hollow." *Kapps v. Wing*, 404 F.3d 105, 124 (2d Cir. 2005).

A. States Must Adhere to Due Process Requirements and Provide Adequate Notice When They Use ADS as a Part of the Benefits Decision-making Process.

Where, as here, a decision to reduce services depends on the results of ADS assessment tools and guidelines, constitutional due process and the Medicaid Act require a notice to include individualized information that explains why the state believes the individual's needs have changed. This is true regardless of the complexity of the assessment tool, related ADS, and the surrounding processes.

See, e.g., Elder, 54 F.4th at 1064 (finding that a notice must explain the reasons for the reduction in services with "specific references (as applicable) to the methodology" of the assessment tool and ADS determining service hours); *K.W. v. Armstrong*, 180 F. Supp. 3d 703, 714-15 (D. Idaho 2016) (stating notice must provide the reasons for the reduction, including both the reasons relied upon to reduce the assessment scores, or what was relied upon outside those scores to ensure a full explanation in all instances); *M.A. v. Norwood*, 133 F. Supp. 3d 1093, 1100 (N.D. Ill. 2015) (recognizing that "[a]n agency must provide specific reasons for how the decision was reached"); *Waldrop v. New Mexico Hum. Servs. Dep't*, Civ. No. 14-047, 2015 WL 13665460, at *23-24 (D.N.M. Mar. 10, 2015) (Aa0136-38) (holding notice must inform beneficiaries of the factual issues that had been resolved by the assessor and resulted in reduction or elimination of benefits); *L.S. ex rel. Ron S. v. Delia*, No. 5:11-CV-354, 2012 WL 12911052, at *14 (E.D.N.C. Mar. 29, 2012) (rejecting notice of benefit reductions based on assessment tool score as inadequate where it failed to provide sufficient information for participants to "understand the score" or "how the score was reached").[2]

[2] Pursuant to R. 1:36-3, counsel includes unpublished opinions in the appendix. Counsel offers the opinions for the limited purpose of providing information on how some courts have analyzed due process issues in similar cases involving ADS, including assessment tools, guidelines, and budget matrices. Counsel is aware of no cases that are contrary to that limited proposition.

The decision in *Waldrop* offers an example of inadequate notice based on the use of an assessment and ADS to set service budgets. 2015 WL 13665460, at *23-24. There, the District Court of New Mexico found multiple due process issues with the way the state Medicaid agency implemented an ADS assessment tool to determine home and community based service budgets for beneficiaries with developmental disabilities. *Id.* Given the lack of explanation about the assessment tool's role in setting the budgets, the court concluded that the notice violated due process because it left beneficiaries with "inadequate information to mount a successful appeal." *Id.*

B. Due Process Requires the State and Its Agents to Employ Ascertainable Standards When Making Decisions About Public Benefits.

In addition to requiring an adequate notice and opportunity to be heard when Medicaid coverage is denied or terminated, constitutional due process also requires state agencies to tie eligibility and coverage to standards that are ascertainable to the public. *Holmes v. N.Y.C. Hous. Auth.*, 398 F.2d 262, 265 (2d Cir. 1968) (finding due process requires states to use "ascertainable standards"). A number of courts have cited *Holmes* to support requirements that public benefit programs, like Medicaid, be administered according to ascertainable standards. *See, e.g., Carey v. Quern*, 588 F.2d 230, 232 (7th Cir. 1978); *K.W.*, 180 F. Supp. at 715 (collecting cases); *M.A.*, 133 F. Supp. 3d at 1098 ("To ensure fairness and to prevent arbitrary decision making, due process requires eligibility for

government assistance programs to be determined according to articulated standards."); *Strouchler v. Shah*, 891 F. Supp. 2d 504, 515-16 (S.D.N.Y. 2012) ("[D]ecisions regarding entitlements to government benefits [must] be made according to ascertainable standards that are applied in a rational and consistent manner." (alteration in the original)); *Pressley Ridge Sch., Inc. v. Stottlemyer*, 947 F. Supp. 929, 940 (S.D.W. Va. 1996) ("Due process further requires that decisions regarding entitlements to government benefits must be made according to 'ascertainable standards' that are applied in a rational and consistent manner").

The requirement for ascertainable standards when the state Medicaid program is using an ADS is illustrated by *T. v. Bowling*, 2:15-CV-09655, 2016 WL 4870284, at *11 (S.D.W. Va. Sept. 13, 2016), *modified sub nom. Michael T. v. Crouch*, 2018 WL 1513295 (S.D.W. Va. Mar. 26, 2018). The court examined the procedures surrounding an algorithm used to calculate individualized budgets for Medicaid beneficiaries with intellectual and developmental disabilities. The notice sent to the beneficiaries identified the budget amount calculated by the ADS but did not include any additional information about the ADS. *Id.* at *10. The developer said the ADS was proprietary, and the state agency did not know individual variables incorporated into the algorithm or how each variable was weighted. *Id.* at *9. Finding this process did not employ ascertainable standards, the court emphasized:

> [I]n the present case, the lack of transparency surrounding the proprietary APS Algorithm renders Defendant's individualized budget determinations potentially—if not effectively—standardless. Such a potentially rudderless determination creates a high risk of arbitrary and erroneous benefits determinations and, as such, is impermissible under the Due Process Clause.

Id. at *11.

Similarly, the Ohio Court of Appeals has found a lack of ascertainable standards where an undisclosed assessment tool was a "decisive measure" in cutting approved hours of in-home services for Medicaid beneficiaries. *Mocznianski v. Ohio Dep't of Job & Fam. Servs.*, 960 N.E.2d 522, 529 (Ohio Ct. App. 2011). Although the Department refused access to the ADS that interpreted the assessment questionnaire, it maintained to the court that the program considered all of the statutorily mandated factors in determining the in-home services. *Id.* at 525. The court rejected this assurance, explaining that "without examining the weight given to each of those factors, it is impossible to ascertain whether something is amiss." *Id.* at 528. The court further held that the individual was denied due process, noting: "It is simply unimaginable that the operation of such a device should not be disclosed to an individual whose benefits are in jeopardy by its application." *Id.* at 529; *see Goldberg*, 397 U.S. at 268 (stating that adequate notice protects against adverse agency action "resting on incorrect or

misleading factual premises or on misapplication of rules to policies of the facts of particular cases").[3]

Finally, contracts with third-party entities cannot deprive Medicaid beneficiaries of their rights to information about how the Medicaid program works and how the program's rules have been applied to their individual cases. *See K.C. ex rel. Africa H. v. Shipman*, 716 F.3d 107, 112 (4th Cir. 2013) (stating that Medicaid's single state agency requirement establishes "an accountability regime in which that agency cannot evade federal requirements by deferring the actions to other entities"); *Salazar v. D.C.*, 596 F. Supp. 2d 67 (D.D.C. 2009) (holding that copyright and local trade secret laws do not trump the federal Medicaid statute and regulations). *Salazar* illustrates the problems that arise when licensed assessment tools are used for Medicaid benefits decision-making. 596 F. Supp. 2d at 68-69. In *Salazar*, a plaintiff class sought disclosure of clinical coverage guidelines, including for nursing services, developed and copyrighted by

[3] In this case, MCG's refusal to disclose what factors the PDN Acuity Tool considers, see Tr. 124:2-16, raises many of the due process concerns discussed here. And because a child is involved, there are additional concerns. For example, it is unclear whether the ADS tool incorporates and applies the Medicaid's heightened coverage standards for children. These coverage standards are required by the Medicaid Act Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provisions. *See* 42 U.S.C. §§ 1396a(a)(10), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r). Among other things, EPSDT requires states to ensure that a child has access to any Medicaid-coverable service, as listed in the Medicaid Act section 1936d(a), when needed by the child to "correct or ameliorate" their physical or mental condition. See 42 U.S.C. § 1396d(r)(5) (setting forth EPSDT medical necessity standard).

McKesson. *Id.* at 68. McKesson refused to disclose the guidelines, claiming they were protected proprietary information. *Id.* at 69. Finding "no authority for the proposition that the federal copyright laws and local trade secret laws trump the federal Medicaid statute and regulations," the court ordered disclosure of the guidelines pursuant to a protective order. *Id.* at 69-70. Notably, when balancing the commercial interests of McKesson against the health and welfare of the plaintiff class, the court was heavily persuaded by the challenges faced by parents and caretakers of children with disabilities, noting the challenges managing necessary care as well as "the difficult intellectual tasks of understanding what services are available to their children, under what conditions, and for what duration, so that they can make responsible decisions for their care." *Id.* at 69. In sum, the constitutional right to understand the criteria by which Medicaid services are approved is well-established and does not yield to commercial protections.

CONCLUSION

For the foregoing reasons, *amici* ask the Court to reverse the final agency decision.

Dated: March 16, 2023

Respectfully Submitted,

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